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This Is Herpes: A Qualitative Investigation of the Disclosure Patterns of HSV2  
Individuals

Katrina Miles

A thesis submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

Partial Fulfillment of the Requirements

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## ABSTRACT

It is estimated that by 2025, 49% of the female population and 39% of the male population, aged 15-39, will have contracted herpes simplex virus 2, or as it is more commonly known, genital herpes (Fisman, Lipsitch, Hook & Goldie, 2002). However, little is understood about the ways that those with genital herpes communicate their condition with potential partners, friends, or family members. Using in-depth qualitative interviews this research focuses on understanding the unique patterns that individuals with genital herpes engage to disclose their status to significant others. Utilizing the theories of Communication Privacy Management and the Disclosure Decision-Making Model we begin to investigate the impetus and the barriers for disclosure of a genital herpes status. Those with genital herpes disclose their status to protect themselves or partners, obtain emotional support, alleviate a known situation, or to maintain relationships. It emerged that those with genital herpes are more likely to refrain from disclosure due to a fear of stigmatization or a desire to control personal information. This research indicates that there is more to understand about genital herpes disclosures and provides the practical information that health practitioners should give to those recently diagnosed to help them process their new reality.

## CHAPTER 1: INTRODUCTION

*With a lethargic tap of my finger, the classes I'm meant to teach for the day are cancelled. Perhaps I should have tried harder to get out of bed this morning. But my head is pulsating and the weak light finding its way through my windows is burning my eyes. My stomach, usually an iron cage, has sprung a leak like the Titanic, now gushing with acidity, raging its way up my esophagus. I am trapped on the bed, weighed down by the awareness that I should have had my test results two days ago. It is amazing how the body seems to know more than the brain is willing to admit.*

*Ring.*

*A simple phone call has turned into a piercing alarm, simultaneously obtaining my attention and telling me to run away from it. An unknown local number. It could be anyone, I cerebrally argue. But the knots in my stomach that have made a cushion for my heart knows better.*

*"Hello."*

*"Hi, is this Katrina?"*

*If only I could be someone else, "Yes."*

*"Hi, this is Peggy, from the health center. Are you able to talk?"*

*"Sure."*

*"So, your test results came back, and I'm sorry but...."*

*The click of the line the apparent end of the conversation. I've never experienced any symptoms, but apparently, you don't have to when you have herpes.*

*HERPES.*

*A diagnosis you don't want to make sense of.*

*H.*

*Hearing news that you can never unhear*

*E.*

*Exposing diseased flesh to every partner*

*R.*

*Remembering every encounter that could have brought you to this point*

*P.*

*Panic seeping through every pore*

*E.*

*Escaping breath that you can't remember how to make return*

*S.*

*Slutty behavior is how you got here*

*This is how it feels to have genital herpes.*

*A lost sense of time means that it is suddenly afternoon before I am able to take my taffy coated self through the initial shock to call someone to help me. I haven't gone into a panic yet, but the long claws of fear are mildly tapping away, waiting for their turn. Dressing, touching betraying flesh seething beneath the surface. Burning with every accidental graze.*

*Panic does not need your scream, though it will take it too, it is more than happy to gorge itself on any emotion set before it. Laughter, for example, the moment you try to make light of the situation and chuckle to your friend. A single instant of humor stretched to its breaking point, turned up to the highest decibel, transforming into hysterical noise.*



*Panic scratching into your head as if it's defending its place within your soul. Using irrational thoughts as bullets to leave you tattered. Screaming to remind you that you are just...*

*H.*

*Heaving stomach full of disgust*

*E.*

*Every future partner put at risk*

*R.*

*Regret for all past pleasure seeking*

*P.*

*Pretending that it's not that bad*

*E.*

*Expecting to be alone forever*

*S.*

*Sick always, but never symptomatic*

*Contaminated, infected, diseased*

*Forever*

*Always*

*Alone.*

\*\*\*

When it comes to genital herpes, no one is alone, according to the World Health Organization (2016), globally, an estimated 417 million individuals currently carry the herpes simplex virus-2 (HSV-2) infection. Of that number, the Centers for Disease Control and Prevention (2015b) indicated that 50 million of those with the infection are in the United States and 776,000 new cases are estimated to be added each year. Nearly half of those new cases (45%) will impact those between the ages of 15-24 (CDC, 2015a). If current trends continue, Fisman, Lipsitch, Hook, and Goldie (2002) estimated that by 2025, 49% of the female population and 39% of the male population, aged 15-39, will be living with genital herpes. As hinted by the estimates from Fisman et al. (2002), this infection does not impact populations equally.

### **HSV-2 Determinants**

Although there is the idea that STIs impact the population equally, certain populations experience higher rates of prevalence, including those impacted by HSV-2. For example, females (20.3%) have a higher infection rate compared to males (10.6%), partially due to biological factors (CDC, 2015). The vagina has columnar epithelium cells that are especially prone to sexually transmitted infections (Eng & Butler, 1997). These cells descend and ascend from the inner cervix to the vaginal surface at various points of a female's life. The exposure of columnar epithelium cells during puberty and young adulthood on the vaginal surface increases the likelihood that a female will become infected with an STI, including genital herpes. Genital herpes transmission rates also

disproportionally impact women. The chance of a source female<sup>1</sup> transmitting genital herpes to a non-source male partner is much lower than the transmission rates of a source male transmitting the infection to a non-source female partner, 4% to 10% comparatively (Herpes Opportunity, 2013). If a source individual uses protective behaviors, condoms or medication, this risk is reduced to 5% for females and 2% for males; risk is further reduced (2.5% and 1%) if both condoms and medications are used correctly and consistently. At the time of this thesis, there seems to be no research about female-female or male-male transmission rates, potentially indicating heteronormalizing in STI research. In order to be inclusive, all relationship types, heterosexual, homosexual, bisexual, and pansexual, will be included in this thesis.

The female population is not the only group unequally impacted by genital herpes. Those who racially identify as “non-white” are also impacted by higher levels of incidence of genital herpes. Non-Hispanic blacks (39%) become source individuals at three times the rate of non-Hispanic whites (12%), with Non-Hispanic black females (48%) carrying most of that burden (CDC, 2010). Even when controlling for number of partners, non-Hispanic blacks (34%) are still at higher rates of incidence compared to non-Hispanic whites (9%) and Mexican Americans (13%) (CDC, 2010). It is likely that within the six years since the CDC numbers were released that these rates have only increased. Regardless of these populations, the CDC estimated that the majority (84%) of those who carry the infection, between ages 15-49, have never received a clinical diagnosis and are unaware of their condition (CDC, 2015).

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<sup>1</sup> Source individual is the partner that carries the HSV2 infection. Non source individual is the partner who is at risk of transmission.

One of the primary reasons individuals are unaware of their condition is the lack of physical symptoms related to genital herpes. While the physical symptoms of this virus are painful blisters located on the genitals, mouth, or anus, most of those who are infected are asymptomatic, meaning they do not show any signs of the infection (CDC, 2016). Others have symptoms so mild they can be associated with some other ailment, including symptoms that resemble the flu. Those who do suffer from visible outbreaks have ulcers from the splitting of the blisters around the mouth or genitals which can take up to four weeks to heal (CDC, 2015). Fortunately, after the initial herpes outbreak, recurrent outbreaks tend to decrease in severity and duration. Whether an individual is asymptomatic or not, they now must decide – who do they tell?

### **Communication and Disclosure**

Management of disclosure is an element of STIs that all source individuals will need to negotiate. Research on disclosing patterns of those with other STIs include HPV (Harvey-Knowles & Kosenko, 2012; Kosenko, Craig, & Harvey-Knowles, 2012; Kosenko, Harvey-Knowles, & Craig, 2015; Smith et al., 2014) and HIV/AIDS (Catona, Greene, & Magsamen-Conrad, 2015; Catona, Greene, Magsamen-Conrad, & Carpenter, 2016; Greene & Faulkner, 2002; Wilkerson, Fuchs, Brady, Jones-Webb, & Rosser, 2014). The studies that exist surrounding disclosure have focused on STIs in general, which may or may not include genital herpes (Balfe & Brugha, 2010; Hullet, 2004; Nichols, 2012). Ports, Reddy, and Barnack-Tavlaris, (2013) did specifically study genital herpes, focusing on patient-provider communication. In their study, disclosure of source individuals was only addressed as a byproduct of providers who engaged in patient-centered communication. Although it is important to understand how providers impact

the disclosure process, it is also necessary to see how individuals interpersonally negotiate disclosure with non-medical individuals, such as sexual partners.

Once a diagnosis of genital herpes has been made, individuals will begin the process of choosing if, when, and to whom to disclose this information. Individuals who made the decision to disclose to partners about their HSV-2 largely based their decision on the seriousness of the relationship and the desire to be honest (Bickford, Barton, & Mandalia, 2007; Myers, Buhi, Marhefka, Daley, & Dedrick, 2015; Green et al., 2003). Non-disclosure of STIs, including HSV-2, was associated with fear of rejection/reaction from partner (Myers et al., 2015; Green et al., 2003), the worry information will spread (Newton & McCabe, 2008a; Green et al., 2003), and the belief that source individuals were not participating in risky behavior through use of condoms and medications (Green et al., 2003). Casual relationships are especially prone to non-disclosure due to a perception of lack of risk and non-seriousness of relationship (Bickford et al., 2007; Green et al., 2003). Individuals with genital herpes disclosed based on their perception of the relationship, even when there are significant consequences associated with non-disclosure.

When a source individual makes the decision not to disclose their HSV-2 status, there can be negative consequences for both the individual and their partner(s). Newton and McCabe (2008b) found that non-disclosure of STIs, including HSV-2, led to higher rates of sexual anxiety and sexual depression along with lower rates of sexual esteem and sexual satisfaction for source individuals. Non-disclosure becomes especially troubling when combined with Wald, Krantz, Selke, Lairson, Morrow, and Zeh's (2006) findings that transmission rates were reduced by half when the source partner was aware of their

status and disclosed it to their partners. However, the blame of non-disclosure cannot be shouldered by source individuals alone, as many indicated that they never disclosed because they were never asked by partners (Meyers et al., 2015). This calls into question who should be considered responsible for discussions surrounding sexual history, a source individual, a non-source individual, or both. The strong negative implications of non-disclosure of genital herpes status, especially when considering transmission prevention, warrants further research.

The commonplace and asymptomatic nature of genital herpes creates an interesting focus on the determinants of disclosure. Those with genital herpes will always have to consider whether or not to disclose their status. This ongoing disclosure process including its impacts on source individuals warrants a further understanding that we do not currently have. While the small majority of those with genital herpes (54 %) disclose to all partners, many still choose not to disclose (Bickford et al., 2007). As Cook (2011) found, many individuals feel morally obligated to disclose their status, but they do not have the support to be able to do so. Through this investigation we understand that there exist specific patterns of disclosure utilized by those with genital herpes, which are often engaged despite little direction from their disclosing practitioner.

### **Thesis Preview**

This thesis fills the gap in the communication literature by exploring the patterns of disclosure and non-disclosure of those who have genital herpes. I use qualitative inquiry to interrogate the topic, utilizing in-depth individual interviews.

Chapter 2 focuses on reviewing literature surrounding other sexually transmitted infections and genital herpes. The focus of much of Chapter 2 will be about the current

notions of the communicative disclosure process of sexually transmitted infections. As noted throughout Chapter 1, the literature specific to disclosure and genital herpes is lacking; however, the communication literature about disclosure related to other sexually transmitted infections will provide a useful vocabulary to make sense of genital herpes disclosure. The finished chapter will also provide a framework for the not yet identified theory that will emerge during the analysis process. As discussed in Chapter 3, I will be conducting an emergent thematic analysis using the constant comparative method, a type of grounded theory.

Chapter 3 lays out the structure of how this thesis will be completed. The chapter will explore why qualitative methods, including why interviews and autoethnography, were chosen for this project. Additionally, this section will argue for the inclusion of these methods and their significance to understanding the disclosure process of those with genital herpes. A detailed account of all measures taken to obtain the data will be provided, along with support for its rigorousness and validity.

Chapter 4 discusses the themes which emerged from the in-depth interviews about the disclosure patterns of those with genital herpes. The data will be organized by the emergent themes and descriptive illuminating examples will be used.

Chapter 5 investigates the information that those with genital herpes wished that others would be cognizant of when giving or receiving a positive diagnosis. These others include practitioners who are giving the original diagnosis, those who have recently been diagnosed, and those who might experience a person disclosing a positive status to them. Within this section recommendations are given to practitioners to better support those who have recently been diagnosed.

The final chapter will bring all the component pieces together into discussion. This chapter will discuss the theoretical and practical implications of the findings from Chapters 4 and 5. This chapter will conclude with potential limitations of the research and directions for future research.



## CHAPTER 2: LITERATURE REVIEW

*“You know, one day I am going to write a book and one of the chapters is going to be called, ‘That Time I Dated an Ex-Con and Found Out I Had Herpes, Coincidentally Two Related but Unrelated Events’” I admit to Noelle smiling. I rest my hand on the table of her, barely big enough for two, breakfast nook, in her, barely big enough for two, kitchen. Light streams through the windows reflecting off the country white cabinetry. Everything is bright and shiny, as kitchens should be. Inhaling down to my toes, letting nostrils fill with long lost smells of meals past. Meals made with laughter and comfort and love. To be in a kitchen is to let those moments wrap around, a childhood blanket providing peace. Plus, kitchens are clean unlike...*

*The space becomes crowded as her husband, Dean, meanders through the kitchen working on whatever project had recently caught his interest. He laughs, but doesn’t comment.*

*“Oh, come on!” Noelle chides, “You’re more creative than that!”*

*I chuckle hollow and forced, but at least no hysteria. Already had a mental breakdown, the shadow lurking beneath the surface, waiting for a crack. One tiny hole to burst through like a zit squeezed to its breaking point, residue on the mirror. Another mess to clean up. Hard to do when it’s you who is dirty. A slimy puss filled body no loofah can exfoliate.*

*Stop it!*

*Why? It’s true.*

*No, it’s not!*

Yes, it is. Are you not diseased?

*Shadows edge closer swirling toward the split, its curling fingers reaching out to undo me. The light in the kitchen seems dimmer now. Swallowing hard, my sweaty palms leaving imprints on the table. Eyes widening to keep the pinpricks of tears from falling down my face as I grind teeth against inner cheeks. Chills creep up a spine that no blanket can cure.*

*Focus on the facts!*

*Fact one: I have herpes simplex virus-2 aka genital herpes.*

*The shadows seem to hesitate.*

*Fact two: It's not one of the STIs that can be cured.*

*Clawing fingers contact nothing but air.*

*Fact three: I was responsible and told my last and current partners.*

*Stuffed back into their box.*

*Fact four: I'm fine, it's just a new part of my life now*

*Light returns to the room.*

*Fact five: One of those things was a lie.*

*Gone, but not forgotten.*

*Fact.*

*Fact.*

*Fact.*

*Fact.*

*The fact of the matter is I did not plan on disclosing to Dean when I came over. I needed to disclose to Noelle, needed an older female figure to whom I could unburden. Couldn't tell my mom, not yet, that was a conversation I just was not ready to handle. Plus, I knew that Noelle would help me laugh about the whole situation. We could sit down at the table and I could hash out all the dirty details without external judgement. She would remind me of how great of a paper or poem or performance that this could all be in the end. Encourage me to write about it so I could work through it, or rather in it. It's not the end, only the beginning to a top research paper.*

*"Remember that guy..." I stop, seeing Dean poke his head around the corner looking for something. Why did I think he wouldn't be here? It's weird to ask for privacy in someone else's kitchen, right? The kitchen is the only place I can see having this conversation though. My three previous disclosures were all one-on-one and I looked them straight in the eye. But, maybe I didn't have to engage in that way every single time. There has to be more than one way to disclose my genital herpes and various disclosure patterns would be good source material. Writing about this experience means I'm going to be disclosing all the time, might as well get used to it.*

*I look from Dean to Noelle and back again. It doesn't matter if they both know.*

*Sticking to the facts will make everything okay.*

*Deep breath, begin.*

\*\*\*

When a person receives a diagnosis, whether a mundane cold or the unexpected STI, they must manage this health information (Greene, 2009). As individuals assume a right to control private information (Petronio, 2002), those with a health diagnosis must begin to manage whether to reveal or conceal their diagnosis. This begins the disclosure process, which has been theorized by many communication scholars especially in health contexts. The proposed theories have not been used extensively in understanding the disclosure process of those with STIs', however, research has been conducted to uncover their prominent patterns.

### **Disclosure of STIs**

The disclosure process of those with STIs has been researched to some degree. There is often a morality linked to the notion of disclosing a STI, where those with the diagnosis feel responsible for the health and well-being of their partners resulting in their disclosure (Newton & McCabe, 2008a; Cook, 2011). Newton and McCabe (2008a) found that while the majority of individuals disclose to all partners, some choose to withhold this information. Nondisclosure of STI status, however, was determined by Newton and McCabe (2008b) to increase sexual anxiety and depression. Conversely, those who have disclosed STI status to partners had higher levels of sexual esteem and were more sexually satisfied (Newton & McCabe, 2008b). The decision to disclose an STI has moral implications that can impact an individual positively or negatively.

Unlike cancer or heart-related conditions, STIs have an attached stigma, which can create differences in disclosure practices when compared. Although STIs have various levels of severity, the shared stigmatization of the infections initiate similar circumstances. Of the STI disclosure patterns researched HIV/AIDS, (Allen,

Timmerman, Ksobiech, Valde, Gallagher, Hookham, Bradford, & Emmers-Sommer, 2008; Catona, Greene, & Magsamen-Conrad, 2015; Catona, Greene, Magsamen-Conrad, & Carpenter, 2016; and Greene, Carpenter, Catona, Magsamen-Conrad, 2013) and HPV (Kosenko, Harvey-Knowles, & Craig, 2015; Kosenko, Craig, and Harvey-Knowles, 2012; and Harvey-Knowles & Kosenko, 2012) tend to be at the center. HIV/AIDS and HPV are linked to hefty health concerns, which makes for opportunities of overlap between disclosure patterns. However, as experiences of HIV/AIDS or HPV are not identical, there exists a potential for differences surrounding disclosure.

Many instances lead to an individual choosing not to disclose their STI status to a partner. Individuals cite non-disclosure for HIV/AIDS and HPV due to a fear of rejection or stereotyping (Catona et al., 2016; Keller, von Saovszky, Pankratz, & Hermesen, 2000). Additionally, for HIV/AIDS patients anticipated negative responses and a desire to maintain privacy were precursors for non-disclosure (Catona et al., 2016). When considering a disclosure recipient, HIV/AIDS individuals restricted disclosure if the desired other had too much going on in their lives already (Green et al., 2013). For HPV individuals, non-disclosure related to a perception of lack of risk to partner due to non-intercourse related sexual activity and use of condoms (Keller et al., 2000). Those with HIV/AIDS and HPV each engage in non-disclosure practices as part of their diagnosis management.

While those with STIs may refrain from disclosing their status, others choose to discuss their diagnosis. Individuals disclosed their diagnosis of HIV/AIDS or HPV in order to gain acceptance or express catharsis (Catona et al., 2016; Kosenko et al., 2012). Kosenko et al. (2012) found individuals felt disclosure was a “necessary evil” to obtain

support for their HPV diagnosis and those who were unable to disclose felt cut-off from receiving it (p.359). Additionally, for HPV patients, there is a high disclosure rate for primary partners after the initial diagnosis (Keller et al, 2000; Marhefka, Daley, Anstey, Vamos, Buhi, Kolar, & Giuliano, 2012). For individuals with HIV/AIDS, disclosure occurred when there was a positive anticipated response and/or it was a close significant relationship (Catona et al., 2016). To gauge anticipated response of recipients, HIV/AIDS individuals deployed incremental disclosure, practicing disclosure in stages, as a protective shield (Catona et al., 2016 and Catona et al., 2015). An individual's disclosure of STI status is dependent on their perception of the benefits, relationship, and response.

### **Genital Herpes Disclosure**

Although there are instances of nondisclosure, 54% of individuals with genital herpes disclosed to all sex partners, albeit 31% of those disclosures occurred after having sex and only 44% occurred before (Bickford et al., 2007). There is a discrepancy in the literature as to the primary factors involved in disclosing a genital herpes status. In the study conducted by Green et al. (2003), the risk of transmission to a partner was not the primary factor in disclosure; rather it was situationally dependent on the relationship. Disclosure was more likely to occur if couples were discontinuing condom use or moving in together which indicated a commitment to each other that required honesty, along with the inability to hide symptoms and medication. However, Myers et al. (2015) found that concern for a partner's health and protection were the primary factors in disclosure; other factors concerned relationship length, seriousness, and commitment. Whether is it about fear of transmission or importance of relationship, those who disclosed to their partners about their genital herpes reduced transmission rates to that partner by half (Wald et al.,

2006). When disclosure can impact transmission rates it is imperative to comprehend the patterns of these disclosures to increase their facilitation.

Similar to the research conducted for HIV/AIDS and HPV, those who choose not to disclose their genital herpes status often refrain from a fear of rejection or a negative reaction from partner, including being seen as unfaithful or promiscuous (Green et al., 2003; Myers et al., 2015). Green et al. (2003) also found that non-disclosure occurred due to fear of their status being spread to unknown others. By refraining from disclosing to partners, individuals with genital herpes hope to prevent the stigma associated with the disease (Bickford et al., 2007). Protection of self from stigma often outweighs the protection of partner from transmission in casual relationships, resulting in more instances of nondisclosure of status (Bickford et al., 2007; Green et al., 2003; Oster & Cheek, 2008). Additionally, nondisclosure occurs, according to Myers et al. (2015), due to non-source individuals not approaching the topic, again, calling into question the location of responsibility for safe sex communication. Like HPV, genital herpes nondisclosure occurs if a perception of non-risky behavior is adopted. Green et al. (2003) determined that individuals did not see themselves as engaging in risky behavior if they used condoms, controlled their condition with medication, or avoided sex when displaying symptoms. The problem, noted in Chapter 1, is that in all of those instances there is still some risk of transmission. As such, there seems to be a disconnect between individuals' perception of risk and their actual risk of transmission to partners, casual or committed.

## Theories of Disclosure

Self-disclosure is any moment in which a person divulges personal information to another who had previously not been privy (Derlega, Metts, Peronio, & Largulis, 1993). Altman and Taylor (1973) first proposed the term “self-disclosure” in conjunction with social penetration theory, which claimed that relationships are primarily built through moments of disclosure. Initial disclosures often contain surface-level information sharing, which progressively becomes more intimate as disclosures increase in frequency and detail (Altman & Taylor, 1973). The authors also concluded that levels of disclosure are dependent on whether the individual sees any benefit in the disclosure on the relationship. The influence of disclosure on relationships warrants a further investigation as to how individuals engage in the disclosure decision-making process.

One theory tends to be the stepping stone for additional theories to follow and develop. This remains true in the case of disclosure, leading to Communication Privacy Management (Petronio, 2002), Disclosure Decision-Making Model (Greene, 2009), the Model of Disclosure Decision Making in a Single Episode (Green, Derlega, & Mathews, 2006), Cycle of Concealment Model (Afifi & Steuber, 2010), and the Revelation Risk Model (Afifi & Steuber, 2009). Each theory has investigated the ways in which people manage and share private information with others. However, due to different frameworks and theoretical conceptions the aforementioned models are unable to provide a cross-theoretical perspective. Magsamen-Conrad (2014) used the notion of anticipated reaction as a way to create a more consistent understanding across theoretical frameworks. Anticipated reaction, according to Magsamen-Conrad (2014), is the predominant factor that influences the disclosure process across theories and consists of both anticipated



responses and anticipated outcomes. Anticipated responses are the immediate reactions that individuals feel might happen should they disclose certain information. Conversely, anticipated outcomes are the long-term reactions that individuals perceive. The ability to cross-theoretically understand disclosure is beneficial; however, it is also important to note the dimensions of at least two of the major theories.

### **Communication Privacy Management**

The theory of Communication Privacy Management (CPM) was born from the desire to further understand the general idea of disclosure (Petronio, 2004). Using Altman and Taylor's (1973) Social Penetration Theory, Petronio began her investigation about the conditions of disclosure and what it meant to attempt to control private information (Petronio, 2004). After years of research, Petronio (2002) laid out five primary suppositions and three rule management processes theorizing the ways in which people manage the rules for their private information.

#### **Theoretical suppositions.**

***Private Information.*** The first supposition deals with the notion that CPM centers disclosure on private information. According to Petronio (2002), CPM is separate from previous theories about disclosure due to the distinction made between the concepts of intimacy, disclosure, and private information. Revealing private information is an act of disclosure; however, it should not automatically be considered an act of intimacy. Disclosing private information does not always equate to increased intimacy within a relationship, even if it can be a potential outcome (Petronio, 2002). The concept of private disclosure allows for a multitude of reasons individuals may engage in revealing information, other than attempting to establish a closer more intimate relationship

(Petronio, 2002). In terms of those with genital herpes, disclosing a private status is used to initiate deeper feelings of closeness with a significant other. However, if the relationship with a receiver is not considered significant the goal for the disclosure changes and there could be instances of non-disclosure to limit intimacy and access to private information.

***Privacy Boundaries.*** Petronio's (2002) second supposition argues that because individuals have private information, they are entitled to maintain that privacy through the enactment of boundaries. Boundaries, for Petronio (2002), are categorized as either personal or collective. Personal boundaries surround personal private information not shared with specific individuals. It is important to note that what is considered a personal boundary in relation to one individual may not be the same for another. For example, with a new partner is often a personal boundary surrounding genital herpes status', however, this private information may have been shared with a previous partner or friend.

When a person decides to reveal private information, they are changing a personal boundary into a collective boundary. The collective boundary now encompasses not just the person revealing private information, but the individual who has obtained access to that information (Petronio, 2002). Collective boundaries expand by revealing the private information to additional people, which can be done by the original party or others. The inclusion of others allows collective boundaries to range from dyadic to societal (Petronio, 2002). Boundaries, personal and collective, are not static, but adapt and shift in response to disclosure processes. Petronio (2002) contends boundary management is a complicated process influenced by factors within and outside of personal control. Although one can attempt to control revelations of private information, once revealed the

collective boundary may become turbulent due to ambiguity about who now controls the information. Those with genital herpes do not disclose their status due to control concerns surrounding collective boundaries, including fears about their information spreading to others. Additionally, people with genital herpes constantly have to negotiate collective boundaries. For example, they disclose to certain family members, but not others and are thus required to balance those boundaries carefully. This would also require balance on the known family member's part to maintain the collective boundary.

***Control and Ownership.*** Individuals create boundaries due to the belief they should have control and ownership of private information, which is the third supposition (Petronio, 2002). The concept of ownership means private information is considered to belong to the individual whom it is about, and, as such, individuals have the right to reveal or conceal these aspects. Control is then executed by the individual in determining who can have access to the respective private information. The potential personal nature of private information can facilitate a desire to control what is disclosed, especially to mitigate any potential risks associated with revelation (Petronio, 2002). The need to control private information was supported by the research of Ebersole and Hernandez (2016), who found that families dealing with health concerns restricted disclosure to protect personal privacy. People with genital herpes feel an ownership regarding knowledge about their status and thus reserve the right to limit access to this private information. Being able to control others' knowledge about genital herpes status is especially important due to the potential risks of revealing the information, including fears of relationship dissolution or stigmatization.

Levels of control and ownership influence both personal and collective boundaries (Petronio, 2002). Control and ownership of boundaries surrounding personal private information shift when information is shared with others, thus creating co-owned private information. Accordingly, Petronio (2002) argued, once information is considered co-owned there is now a new privacy boundary, which includes considerations for how access to the private information is controlled. Should a person with genital herpes disclose their status, the recipient of the information is now a co-owner whether they wanted to be or not. This brings into question the control and ownership of the new collective genital herpes status boundary. The emphasis placed on the ability to own and control the sharing of private information indicates vulnerability risks associated with disclosure (Petronio, 2002). Disclosing private information, risky or otherwise, places an individual in a moment of vulnerability. Likewise, choosing not to disclose information can also leave an individual vulnerable. Petronio (2002) posited that weighing out levels of risks to benefits is part of an individual choosing their moments of vulnerability. Due to the potential stigma associated with genital herpes those who are infected are especially cognizant of the vulnerability associated with disclosure. As such, they often consider the ratio between risks and benefits when choosing whether to reveal their status. Instances of non-disclosure are often related to a lack of desire to experience a level of vulnerability within a specific moment.

***Privacy Rule Management.*** Petronio (2002) argued for a rule-based management system, the fourth supposition, that individuals use to control and create boundaries. The rule-based management system is comprised of three separate, but related processes: privacy rule foundations, boundary coordination operations, and boundary turbulence.

First, there is the establishment of the foundation of privacy rules, which is accomplished through rule development and attributes. Rule development is influenced through many criteria including culture, gender, motivation, context, and weight of risk versus benefits. Rule development criteria impacts genital herpes disclosure, however, those that have the greatest impact are gender, motivation, and weight of risk versus benefits. Those with genital herpes are more likely to disclose based on their gender in the sense that women have developed rules that encourage sharing of private information with significant others including friends or family. Protection of self and others is a significant motivation for the disclosure of a genital herpes status. Finally, people with genital herpes weigh out the risk or benefits of disclosing their status in determining whether or not it is worth the risk. Each criterion singularly and combined help to form boundaries for private information sharing.

The combination of cultural and gender expectations can influence how disclosure rules are developed. Ngula and Miller (2010) assert that Kamba, a Kenyan tribe, men do not disclose HIV/AIDS status because of cultural and gender restrictions in terms of discussing sex, showing weakness, and the association of HIV with witchcraft. One way that contextual rule development has been explored is through the research of Smith and Brunner (2016) who investigate the disclosure process of the traumatic event, a disruptive event that impacts life (Petronio, 2002), of cancer. Using the blog of Goodall, Smith and Brunner (2016) found the management of private information to be influenced by humor, metaphors, legitimizing co-owner importance, and shifting privacy rules at end-of-life. Motivational aspects, the reason for expression or hindrance of disclosure, have also been explored in the context of health. Ebersole and Hernandez (2016) found that families use

health disclosure and non-disclosure to protect others from stress/worry and risk.

Additionally, disclosure of private information is motivated by an attempt to gain social support (Ebersole & Hernandez, 2016; Petronio & Sargent, 2011). Developing rules associated with genital herpes disclosure could shift based on a person's gender or culture. Women are known to more readily engage in disclosure (Petronio, 2002), which increases the likelihood of discussing their genital herpes status. Additionally, cultural backgrounds limits disclosure of genital herpes due to negative stigmas surrounding premarital sex or discussing personal matters with others. The weighing of a risk-benefit ratio heavily influences the rules associated with genital herpes disclosure, should an individual feel increased risks they could restrict status knowledge therein developing a rule for future use.

The second aspect of privacy rule foundation is attributes, which encompasses acquisition and properties. Petronio (2002) state that individuals acquire the rules for disclosure through socialization and negotiation. Through socialization, practices of family and organization specific rules can be acquired about appropriateness of disclosure. Rules, like the people who create them, are not static and are negotiated through collective boundaries. The interactive process of rule negotiation brings about the necessity for explicit and implicit rules (Petronio, 2002). When negotiating collective boundaries, explicit rules directly inform both parties about who controls and shares the information, i.e. "You can't tell anyone about my genital herpes." Conversely, implicit rules are assumed by both parties, i.e. not sharing genital herpes status because health concerns are never disclosed. Helft and Petronio (2007) found that dissatisfaction of provider hit and run delivery style of bad news was related to patient's implicit rules

about providers sharing in the emotional burden of medical information, as collective boundaries demand.

The balance between explicit and implicit rule making is influenced by rule properties. Rule properties describe the “nature” of rules (Petronio, 2002, p. 79). Rules may be routinized, habitual rule patterns emerge resulting in rule orientations when stable; triggered, changes in experiences instigate rule accommodation; or sanctioned, violators of collective boundary rules are reprimanded (Petronio, 2002). An unexpected genital herpes diagnosis disrupts routinization of sexual health rules and trigger the changing of rules about disclosing current and previous sexual practices.

When privacy rule foundations have been established, individuals may begin to disclose private information based on these rules. By relinquishing private control and embracing vulnerability through disclosure, an individual has shifted from a personal boundary to a collective boundary. Petronio (2002) argued that this shared information is now co-owned within the collective boundary between the discloser and the recipient. The frequency of revealing private information leads to people having to balance multitudes of collective boundaries, ranging from dyads to organizations. Each collective boundary requires certain responsibilities to the shared information, as well as rules about the coordination of boundaries (Petronio, 2002). Boundary coordination occurs through three processes: boundary linkage, boundary permeability, and boundary ownership.

First, boundary linkages occur whenever a personal boundary becomes a collective boundary, either through transformation or appropriation (Petronio, 2002). Boundary linkages are transformed whenever an individual releases private information to another, but are appropriated when collectively shared information is revealed to new

members as a requirement of group membership. Petronio (2002) indicated that although boundaries may be linked, proportional sharing within the boundary and strength of relational ties are not guaranteed. Conventions established during the privacy rule foundation process mitigate the rules of boundary linkages.

Petronio (2002) focused on the consistent factors of confidant selection, timing, topic, and personal characteristics when discussing rules about linkage while acknowledging there are other influencers as well. Disclosure perceptions about confidant attractiveness, gender, status, and their shared intimacy level influence rule behavior (Petronio, 2002). In terms of sexual health, Ngula and Miller (2010) used CPM to discuss how men living with HIV/AIDS in Kenya disclose their status through target selection finding that first disclosures tend to be wives because of associated needs within the relationship. There are also established rules about the timing of disclosing private information. Like a badly timed joke gets no laughs, disclosing private information at inappropriate times can stymie linkage occurrences, however, finding the appropriate moments can foster them (Petronio, 2002). Choosing when to disclose genital herpes status can be difficult to manage due to potential negative perceptions. Mistiming the appropriateness of disclosure may result in negative feelings and damage to boundary linkages.

Boundary linkage rules are associated with the type of information being considered for co-ownership, which Petronio (2002) identified as topic selection. The disclosure of certain topics may be restricted within potential collective boundaries confining boundary linkages. For example, Ebersole and Hernandez (2016) used CPM to discover how families manage boundaries by avoiding certain health topics, including



alcohol and loneliness. Finally, perceptions of personal characteristics, like being an open or closed person, potentially change boundary linkage rules (Petronio, 2012). A person with genital herpes whose self-perception includes openness may have more collective boundaries about their status. However, these boundary linkages may be mitigated from linkage rule interconnections including: topic selection, not discussing sexual health with specific people; timing concerns, choosing before or after specific sexual acts; or confidant status, revealing status to a peer vs. parent. Although not included by Petronio (2002), others have found that humor has been used as a method to manage boundary linkages in relation to health concerns (Ebersole & Hernandez, 2016; Smith & Brunner, 2016). Petronio (2002) noted that boundary linkages are not at the sole discretion of the individual, but are also developed via another's interest in obtaining private information. When significant others ask about current health issues, those with a recent positive genital herpes status are then being encouraged to create a boundary linkage.

To coordinate boundaries, permeability of those boundaries must be considered. Petronio (2002) described permeability as the level of access and protection granted for private information, whether personal or collective. Thick boundaries have low levels of permeability, while thin boundaries facilitate disclosing private information. Boundary thickness is negotiated through rules concerning access and protection. Access rules define who can know the information, how deeply information is shared, the breadth of information disclosed, and the manner of revealing (Petronio, 2002). In terms of protection, Petronio (2002) indicated rules are established within collective boundaries to keep co-owned information private. For example, thick boundaries were erected by families around Kamba men's positive HIV/AIDS status to limit outsider access and

protect from stigma (Ngula & Miller, 2010). Additionally, thick boundaries have been used to protect nurses from unwanted patient disclosure (Petronio & Sargent, 2011).

Done on an individual level, permeability access and protection are easily managed, however, coordination of these rules within collective boundaries can be more difficult. This is due to all individuals within the collective boundary needing to operate off the same rule set to effectively manage boundary permeability. Boundary turbulence, discussed later, occurs when these collective boundary rules are miscommunicated.

The final component of boundary coordination is the consideration for the ownership of said boundaries. Moving from a personal to a collective boundary relinquishes some control of the private information from the disclosing individual to the receiver. Ownership of this information is shared within the collective boundary as well. Difficulties arise, according to Petronio (2002), when discrepancies exist around who owns and controls the boundary about the information. As private information is often personal, the disclosing individual may feel continued ownership and control over information, however, collective boundaries assume that this responsibility is now shared. Disclosing individuals instigate boundary markers, directly or indirectly, to define how control of the collective boundary should be maintained (Petronio, 2002). Bute, Petronio, and Torke (2015) demonstrate the complexity of boundary ownership through research on surrogate health care decision makers who found themselves in a proxy ownership role as patients were unable to convey personal health care information and desires. Those with genital herpes attempt to control collective boundaries surrounding their status by restricting who has access to their positive status, those confidants who are allowed to know are then sharing the responsibility of boundary management. The

concern for those with genital herpes, of course, is that those same confidants will create boundary turbulence by spreading their status.

As with any human communication endeavor, boundary coordination is imperfect requiring management of boundary turbulence. For Petronio (2002), boundary turbulence indicates moments where coordination of boundaries is disrupted in some fashion. Disruptions can lead to a range of emotional reactions and interpersonal problems. Boundaries are impacted by: intentional rule violations, people within the collective boundary knowingly break information disclosure rules; dissimilar boundary orientations, personal levels of permeability and change allowable within collective rule sets; and boundary definition predicaments, dissimilar definitions of public vs private spaces (Petronio, 2002). Additionally, boundary turbulence occurs through boundary rule mistakes, fuzzy boundaries, and privacy dilemmas (Petronio, 2002).

Unlike intention rule violations, boundary rule mistakes are considered accidents (Petronio, 2002). Accidents can occur from errors in judgements, where co-owned information is shared with a third-party before thinking about consequences. For instance, a mother is talking with her daughter about how nice it is to have built such a strong relationship with her son. She expresses that it is only recently that they've opened to each other, and now they talk about everything. The daughter later mentions how much she sees her brother struggling with his herpes diagnosis, shocking the mother. Although there was a dyadic boundary between the daughter and brother the daughter incorrectly assumed that the collective boundary for his genital herpes diagnosis included their mother. While the daughter may have engaged an error in judgment about the boundary, the accident could also be considered a bungling of topic rules. What type of private

information is meant to be withheld or divulged can become confusing resulting in a violation of boundary rules (Petronio, 2002). The daughter hears that the mother and brother talk about everything, forgetting that, for her brother, “everything” excludes sex. Finally, mistakes in timing can bring boundary turbulence when individuals miscalculate when disclosure is appropriate (Petronio, 2002). Telling a partner about a positive genital herpes status after having already had sex could lead to some extreme boundary turbulence problems.

Another factor that creates boundary turbulence is when boundary expectations are fuzzy. Ownership about private information influences the creation of boundaries, but can also result in turbulence if ownership perceptions between individuals are incongruent (Petronio, 2002). There can be differences in ownership rules of what should remain personal private information and what should be co-owned. Deception may be felt by the unknowing partner, but not shared by the non-disclosing individual. Petronio (2002) argued that within non-disclosure, deception may not be the intent but rather an attempt to protect privacy. For example, Nichols (2012) studied the ways CPM relates to how individuals perceive their private sexual history information, indicating that those who do not disclose their sexual history are not intending to be deceptive, but are attempting to control their private information. Boundary turbulence would occur if the source-individual’s partner did not hold that standard and the information was otherwise discovered. The perception of associated risks regarding genital herpes infection and transmission can be vastly different between source-individuals and their prospective partners, which could increase instances of deception and turbulence.

Finally, privacy dilemmas can produce boundary turbulence due to the ambiguous nature of the situation and the need to balance multiple privacy boundaries (Petronio, 2002). One type of dilemma that Petronio (2002) gives is accidental privacy dilemmas where private information is discovered unintentionally. Using the previous example of the daughter disclosing her brother's status, the mother may experience boundary turbulence from the accidental knowledge of her son having herpes. She may become uncertain about the collective boundary with her son or how to handle the situation, including whether to admit her knowledge or share the information with other family members. Additionally, the daughter can experience this dilemma by confusion on whether she should disclose her boundary violation to her brother.

Petronio (2002) dictated that the three management process systems work together to establish boundaries about private information. Boundary turbulences are fixed through re-coordination of boundaries, which are influenced by boundary foundations. The boundary foundations erected can result from boundary turbulences and change perspectives on boundary coordination. Overall, the three management process systems enable individuals to navigate the disclosure process.

***Privacy Dialectics.*** Petronio (2002) posited that there is a constant push and pull between the desire to reveal and conceal privacy. By disclosing, certain levels of privacy disappear, however, disclosing is not possible without a sense of having private information to protect or reveal (Petronio, 2002). There exists then a constant tension where engaging in disclosure or privacy limits the attainment of the other. A person with genital herpes may experience the tension between wanting to reveal their status for support, but also needing to keep their stigmatized condition private to protect

themselves. The individual would then engage in the boundary management processes as an attempt to negotiate personal and collective boundaries, which may help alleviate this tension between privacy and disclosure.

### **Disclosure Decision-Making Model**

Although CPM has been used in health contexts, the theory itself was not created with health communication in mind. The Disclosure Decision-Making Model was developed to understand disclosure patterns when managing health uncertainty (Greene, 2009). By advancing an integrated framework, Greene (2009) provides a model to attempt to predict disclosure decisions. The model incorporates consideration of factors that can influence disclosure practices. Greene (2009) argued that health disclosure is based on three different assessments: information (the diagnosis), the receiver, and disclosure efficacy.

**Information Assessment.** The assessment of information considers five primary factors: stigma, prognosis, symptoms, preparation, and relevance (Greene, 2009). Greene et al. (2012) argued that the assessment of information about a health condition is the foundational component to understand disclosure decisions, anticipate responses, and perceive their efficacy. While any disclosure presents vulnerability and risk (Petronio, 2002), the perception of risk can be elevated when the material of disclosure is considered stigmatizing (Greene, 2009). The DD-MM posits that the likelihood of disclosure decreases as perceptions of stigma increases; however, this may be moderated through perceptions of anticipated response and relational quality. Individuals with genital herpes become less likely to disclose their condition due to the stigmatizing nature of sexually transmitted infections. The lack of disclosure is countered if the

individual with genital herpes believes they may receive a positive response or have a strong relationship with the receiver. Greene's (2009) concept of preparation speaks to the level of information known previously about the disease. Additionally, preparation contends that awareness of symptoms may provide enough information to prepare for the diagnosis. In both instances of preparation, disclosure may be impacted due to the desire to relieve stress after an unexpected diagnosis or obtain additional information about the disease (Greene, 2009). While jokes about genital herpes may be common, individuals who are recently diagnosed often do not have actual knowledge of the infection. Disclosure of genital herpes in these instances could be a method to obtain additional information or resources to begin understanding the condition.

For Greene (2009), prognosis, the determination of whether a disease is treatable, chronic, or terminal, can influence the timing of disclosure of a health condition. If there is a high level of uncertainty surrounding the prognosis there will likely be a delay in disclosure. However, Checton and Greene (2012) argued that when dealing with heart conditions, prognosis uncertainty increases the breadth of topics about the condition with partners. Prognosis uncertainty disclosure is modified when an individual considers the anticipated response (Greene, 2009). Genital herpes is a virus with no known cure, which means that upon diagnosis the individual with the infection knows that they will always carry it with them. The chronic condition of genital herpes influences the ways that an individual engages the disclosure process. Additionally, the non-terminal nature of the virus influences the ways individuals with genital herpes understand and engage disclosure.

Symptoms influence disclosure practices when they become visible or progress to incapacitation for the individual (Greene, 2009). Greene (2009) speculated the higher the visibility of symptoms or the hindrance on daily life, the more likely an individual will disclose a health status. Individuals who are uncertain about the visibility of their symptoms are less likely to discuss the condition with partners (Checton & Greene (2012). Disclosure increases may be attributed to compensating for rearranging schedules to take care of illnesses or by providing explanations for noticeable symptoms to others. Genital herpes is often asymptomatic, but for those who do express physical symptoms the visibility has the potential to push individuals to disclose. However, genital herpes does not have consistent, excessive, long-term detrimental symptoms, which influences an individual's decisions to disclose.

Finally, disclosure rates increase when the diagnosis is likely to impact the lives of the recipient (Greene, 2009). However, it is important to note, that perceptions of stigma and anticipated response may decrease disclosure rates regardless of impact on the other. Even with protection there is a risk of a source-individual passing on genital herpes to a partner. The possibility to infect another individual often goads those already infected to disclose their status. The desire to disclose is limited if the source-individual feels they may receive a negative response or be viewed negatively. The DD-MM claims that the assessment of health information through these five frames influences whether an individual continues to consider disclosure and thereby move on to the next level of assessment.

**Recipient Assessment.** The next level of assessment under the DD-MM is the consideration of the person intended to receive the disclosure information. The



assessment of the receiver evaluates through two factors: relational quality and anticipated response (Greene, 2009). In terms of relational quality, the better that an individual perceives a relationship with another the greater the likelihood of disclosure of the health diagnosis. Additionally, greater relational quality may act as a buffer against perceived stigma of a condition and thereby increase likelihood of disclosure. Anticipated response, for the DD-MM, indicates that if an individual anticipates a positive response from the receiver then the chance of disclosure increases. Conversely, should an individual anticipate a negative response the rates of disclosure decrease. Venetis, Greene, Checton, and Magsamen-Conrad (2015) found that anticipated reciprocity influenced whether cancer patients avoided topic disclosure, if they felt that the intended recipient would not share concerns about cancer diagnosis disclosure was restricted. Additionally, if actual responses are deemed more negative than anticipated future disclosure rates decrease. How the relationship is perceived by a source-individual influences whether they choose to disclose their genital herpes status. If there is strong relational quality a person with herpes is more likely to disclose their status unless they anticipate that the receiver will respond negatively. In this instance, the source-individual withholds their status to protect against negative perceptions from the receiver. Conversely, there are instances where there is a low investment in the relationship, but the disclosing individual believes that the receiver will not react poorly to the genital herpes status and therefore reveals the information. There are also connections between the types of responses received when disclosing genital herpes status and the rates of future disclosures. When it comes to the disclosure process, individuals assess not only

the information of their disclosure, but also the receiver to whom they would like to disclose.

**Disclosure Efficacy Assessment.** The final assessment is disclosure efficacy, which is dependent on the confidence of the discloser in their ability to reveal their private information, in this case their diagnosis (Greene, 2009). Perceived lack of efficacy can prevent disclosure to others (Venetis, et al., 2015) Disclosers may build up confidence in efficacy over time, however, it is dependent on relational quality and anticipated responses. Additionally, the more stigmatizing the health condition, the less likely there is a positive perception of disclosure efficacy (Choi, Venetis, Greene, Magsamen-Conrad, Checton, & Banerjee, 2016; Greene, 2009). Intention to disclose, present or future, can be restricted if there is a perception of potential negative outcomes from disclosing private information. As previously stated, genital herpes is considered a very stigmatizing condition, which manipulates individual's disclosure efficacy from perception of skills to potential outcomes. Disclosure efficacy for those with genital herpes is often compounded by their lack of knowledge about the infection, including basic information about the disease or good disclosure practices.

Smith, Hernandez and Catona (2014) theorized that the DD-MM is useful in understanding what is said in conversations about HPV diagnosis. Investigating imagined responses to a positive HPV diagnosis, Smith et al. (2014) found that themes of responses aligned with the attributes of the DD-MM including assessing preparation, symptoms, anticipated responses, and relational quality. The indication is that the DD-MM can not only predict instances of health disclosures, but also shed light to the information shared within those disclosing conversations.

## **Summary and Research Questions**

By choosing to disclose STI status, individuals are releasing control of private information that could leave them vulnerable to negative perceptions. Although there is basic understanding of the patterns of genital herpes disclosure, with similar patterns found in HIV/AIDS and HPV research, further investigation is necessary to determine how these patterns align with existing communication theories. While there are many theories that discuss the disclosure process, Communication Privacy Management and the Disclosure Decision-Making Model are two lenses that shed light on the patterns of genital herpes status disclosure. Providing a theoretical foundation to genital herpes disclosure could facilitate a better understanding of this specific disclosure process. Previous research has indicated that there are particular patterns that individuals engage to either permit or prohibit disclosure of status, but does not fully engage our theoretical understanding. Hence, this thesis is guided by the following research questions:

RQ1: How do those with genital herpes come to the decision to reveal or conceal their status?

RQ2: What does disclosing their status mean to people with genital herpes?

## CHAPTER 3: METHODOLOGY

*SHIT...shit, shit, shit, shiiiiit. What was I going to say? I know everyone will find out...eventually. Who said it had to be today though? Perhaps next week, or the next. Who have I even told? Eyes dart amongst the faces of my professor and cohort watching them trying to understand each other's expectations. Do they notice my panicked glances? Doubtful, too focused on the directions presented. She guides us through the basis for our seminar paper.*

*"I want this to be beneficial for you all. I mean, it should have a critical focus but it should work for your needs as well, be that for a thesis or eventual publication." Glasses frame eyes I've never seen without make-up. She is another white face in the sea of white faces of my previous professors and my current cohort. Our skin is different, but we share invisible often stigmatized illnesses. Does hers affect her sex life? Does her race change people's perceptions about her illness? She peruses the room attempting to pin us, "So, what are you all thinking about doing?"*

*It is difficult to swallow when a pounding heart manages to take root in one's throat. Tendrils pulsate with each movement of the buzzing bodies around me, all who are avoiding a response. We have no choice but to look at each other as we are circled around, these two forced together tables.*

*Do they know? Do they know? Do they know? Yes...yes, definitely...maybe...I probably told her...we are close enough for that...him...did I?*

*My eyes lock with the blue eyes and blonde hair of my cohort member across the enormous divide, ignoring her furrowed brows. “Are you going to go?”*

*No, she does not know. I would never have engaged in any conversation that would have resulted in my disclosure. We are not of the same tribe, have literally never sat on the same side. Communication stays in the realm of working acquaintances. Green bile rises; how nice it must be to not have to critically engage with society since it caters to your best interests. If only I too could take this course and at the end decide this methodology just wasn’t my thing. I would never have disclosed to someone who cannot see me.*

*There is too much saliva collecting in my mouth. Swallow, stop the burning burbles. Deep breath in, deep breath out. My inner Hermione, the voice of my good student persona, chides, “Your professor has been waiting an awfully long time for someone to answer her.”*

*Pruning shears in hand, I blurt the partial truth, “I’m going to be using this class to write the autoethnography portion for my thesis.”*

*“Yeah, and I’m going to...” a voice begins.*

*The gleaned remains of my heart are back in the cavity of my chest. I want to write about my experiences disclosing my status, but I didn’t comprehend the full scale of being asked to disclose over and over and over again.*

## **Qualitative Inquiry**

I chose to use a qualitative approach for this study in order to develop a deeper understanding of the meanings that drive individuals with genital herpes to disclose. Qualitative scholars, including myself, have a specific interest in how notions of meaning impact the choices humans make in response to particular events (Lindlof & Taylor, 2006). In order to understand how people with genital herpes disclose, it is imperative to use a methodology that incorporates the reasoning behind those choices. By using this mode of inquiry I am better able to accommodate for the notion of context-specific meanings that is excluded within quantitative inquiry (Golafshani, 2003). A central concern for qualitative researchers is how humans define and interpret their social actions within particular contexts (Lindlof & Taylor, 2006). Researchers then take these descriptive actions and unite them to create a larger narrative, which illuminates a deeper understanding (Golafshani, 2003). The notion of situated meaning attempts to combat the quantitative theorizing that human experience can be wholly understood through statistical and quantifiable data. As qualitative research is concerned with contextual meanings and not generalizability, it is an appropriate method to use for stigmatizing conditions, like genital herpes, that might prevent research participation.

The importance of contextual meaning is additionally displayed through qualitative inquiry's naturalistic approach and subjectivity. According to Lindlof and Taylor (2006), the closest approximation to the natural settings of specific behaviors and meanings is the most appropriate way to obtain understanding of those actions. The naturalistic focus does not exclude contrived situations, like planned interviews; however, it does contend that researchers are required to attend to the real-world implications of

their research (Lindlof & Taylor, 2006). Witnessing natural genital herpes disclosure situations is unlikely, which is why I chose to use interviews to collect information about the behavior and its associated meanings as reflections to the natural experiences. A focus on contextual meaning leads credence to the qualitative inquiry notion that truth is subjective. Subjectivity, per Lindlof and Taylor (2006), is the concept that there exist multiple truths and realities within all aspects of human communication. As meaning is a collective social construction, variables exist between what groups of people consider reality and the truth. Although variations exist, qualitative inquiry does not require one interpretation to be held in higher regard than another. For qualitative inquiry, multiple perspectives are simply understood as differences in the social constructions of meaning.

Within qualitative inquiry, subjectivity also encourages the embodied experience of a researcher; being subjective acknowledges the personal perceptions, positions, and biases that researchers carry into the research field. Unlike quantitative scholars, who use external instruments as a means for analysis, qualitative inquiry acknowledges that the researcher is the instrument who is intrinsically involved in the research process (Lindlof & Taylor, 2006). My ability to control and influence the research inquiries, participants, questions, and analysis demonstrates the embodied aspect of the researcher on their research. It is through my subjective embodied experience that readers are exposed to the words of my participants, as well as my own stories.

Another characteristic of qualitative inquiry are the associated sampling practices. Quantitative researchers often focus on obtaining as random of a population sample as possible, which is not the case for qualitative research (Lindlof & Taylor, 2006). Again, generalizability is not the predominant concern for qualitative research, which alleviates

the necessity for large random population samples. Instead, qualitative researchers engage in purposeful sampling, which allows for the selection of participants based on what is considered most appropriate for the situation (Lindlof & Taylor, 2006). In terms of genital herpes research, attempting to utilize random probability can be problematic as access to the population may be restricted due to stigma concerns. As such, purposeful sampling enables me to focus on finding appropriate participants through multiple means.

Finally, qualitative inquiry demands a descriptive and inductive approach to data gathered through research. As qualitative research may not have the breadth necessary for generalizability, there is a shift to the importance of the depth of research. Thick descriptions are a cornerstone of qualitative research; it is necessary to provide enough rich detail to establish understanding (Lindlof & Taylor, 2006). The rich detail elicited through the research sets the foundation for inductive reasoning and extends the value of its interpretations. Inductive analysis requires theory to naturally emerge from the descriptive data (Lindlof & Taylor, 2006). For qualitative inquiry, it is not about prescriptively applying theory onto research data, but rather using the gathered descriptions to develop the themes and theories. Additionally, qualitative research is not about testing hypotheses, but generating overarching research questions that the data will attempt to answer. With this in mind, my thesis started with two prominent research questions that were used to guide the interview protocol. The data was then used holistically to inductively develop themes associated with genital herpes disclosure. Finally, it was through inductive analysis that the emergent theories of CPM (Petronio, 2002) and DD-MM (Greene, 2009) were identified.



## **Research Procedures**

**Recruitment.** Participants were recruited after I received Institutional Review Board approval for this thesis (IRB # 17-0146; Appendix A). Participants in this study were recruited through three different avenues: Facebook, a university list-serv, and word of mouth. The first recruitment tool used was Facebook. Three different Facebook pages were used to recruit participants. A call for participants was placed on my own personal Facebook page and then through two women's advice Facebook group pages. The two Facebook group pages were women-only membership groups and one focused specifically on sexual activities. These two groups chosen were due to my personal involvement in the groups, which provided additional credibility. The two Facebook groups combined had the potential to reach 7,373 participants. There were two waves of Facebook calls for participants. The first call occurred in November 2016 and the second in December 2016. The second recruitment tool used was the James Madison University employee and student listserv. After approval of the email list-serv request, the call for participants was distributed to 4,015 employees and 21,447 students in early December 2016. The final method of recruitment was word of mouth, which occurred by discussing my thesis with those I met.

**Participants.** A total of seven participants were interviewed for this thesis. Two participants were diagnosed with HSV-1 genital herpes, four participants were diagnosed with HSV-2 genital herpes, and one participant was diagnosed with genital herpes but does not have a confirmation of type. The original research call requested that all participants be diagnosed with HSV-2; however, once participants began to respond it was determined that some participants had HSV-1. Herpes simplex virus-1 is colloquially

known as “oral herpes”, however, this label is misleading because the virus strain can present on the mouth, genitals, or both. In both HSV types, when the virus is focused on the genitals, it could initiate the same types of disclosure about sexual activity. All participants had symptomatic herpes, meaning that it was the appearance of physical symptoms that initiated their testing and diagnosis.

All the participants were female. Six participants identified as white and one as Black. Six participants identified as heterosexual and one identified as lesbian; however, one self-identified heterosexual participant did express some sexual interest in females. Participants’ ages ranged from 20 to 36 ( $M = 22$  years). The age of diagnosis varied for participants. Three participants were diagnosed in their late teens (18, 19, and 19), three in their early 20s (20, 23, and 23), and one in her early 30s (31). The participants have been living with their herpes diagnosis ranging from seven months to eight and half years ( $M =$  three and a half years). All participants lived in rural communities. Five participants attended or worked at either a large Mid-Atlantic university or a small liberal arts college.

**Individual interviews.** Individual interviewing focuses on one-on-one conversations between the interviewer and the interviewee. I chose this method in order to clarify personal meanings, develop criteria for decision making, determine influencing factors, and understand motivations related to individual actions (Lazarsfeld, 1944). Interviews allow for a better understanding of individual experiences, in this case disclosing genital herpes status (Lindlof & Taylor, 2006). Lindlof and Taylor (2006) discussed how interviews enable researchers to gain information about events that cannot be observed directly. Due to the inability to witness authentic genital herpes disclosures, participants were asked detailed questions about their disclosure experiences, decision-

making practices, and overall reactions to develop meaningful genital herpes disclosure patterns. Finally, Lindlof and Taylor (2006) described how interviews enable reflexivity which allows for the influence that occurs between the myself, the interviewer, and the interviewee with the interviewing experience. Qualitative interviews require that I engage in meaningful interaction with the interviewee where both of us can build and expand on ideas or comments mentioned by the other. This type of interaction creates a dynamic atmosphere where both of us influence the meanings and perceptions of the other. For example, within this research the questions asked to the participants allowed them to reflect on their experiences of genital herpes disclosure. Through this description, they may be better able to understand their own disclosure processes. Additionally, the expression of participant genital herpes disclosure experiences allows the me to be reflexive about my disclosure practices and the ways that I understand the developing theoretical patterns.

At the start of the interview, I presented participants with the informed consent forms, giving them time to read over the form and ask questions about the study. After any questions were addressed, participants signed the consent forms. Interviews were conducted in private or semi-private spaces, including homes, offices, and cafes. These locations were selected by the interviewees. Six interviews were conducted face-to-face. The remaining interview was conducted over the phone per the participant's request. In this instance, the participant was read the consent form over the phone and gave verbal agreement to participate.

I chose a semi-structured interview protocol for this thesis as it allowed a structured idea of genital herpes disclosure to be developed without restricting the

interview from attending to unlisted concepts that emerged from the conversation (Lindlof & Taylor, 2006). This setup allows for fluidity in the conversation between myself and the participant; in addition, it allows the participants to guide the direction of the interview based on their own experiences with the topic (Lindlof & Taylor, 2006). The interview protocol contained 18 questions (see Appendix B for interview protocol). Protocol questions focused on obtaining information about experiences where participants decided to either conceal or reveal their genital herpes status to significant others including family, friends, and partners. Questions were also asked to gain insight to previous and current sexual practices of participants. Finally, protocol questions covered the experience between the participant and their disclosing health provider, including any advice or techniques they were given for future disclosures. Notes were taken during the interview process for the first participant, and thereafter notes were gathered immediately after the interview due to a lack of connection with participants when writing during the process. In sum, seven handwritten pages of notes were written from the interview pertaining to connections between interviews, theoretical linkages, and personal reflections and feelings. After review of the interviews and notes, it was determined that theoretical saturation was met as the later interviews provided no new patterns or ideas of genital herpes disclosure patterns, instead they just provided support for initial insights.

All participants were recorded using a digital recorder. Interviews ranged from 23 minutes to 75 minutes ( $M = 45$  minutes), for a total of five hours of interview data. Once all interviews were completed, the interviews were transcribed using Express Scribe Transcription Software. Participants were assigned a random number to maintain

confidentiality during the transcription process. Additional identifiable information was also removed during transcription to protect participants' identities. Interviews were transcribed verbatim and resulted in 82 single-spaced pages.

### **Data Analysis**

Emergent thematic analysis, a type of grounded theory, was used as the analysis approach for this research study. I chose this methodology as it allows the relationship between data and its associated patterns to emerge naturally, rather than using theory prescriptively (Lindlof & Taylor, 2006). Grounded theory posits that the categorization of data remains in a fluid-like state until the conclusion of the research, due to the ability of new data to transform perceptions of the categories (Lindlof & Taylor, 2006). Grounded theory enables researchers to analyze the emergent themes to develop from the data. This type of analysis consists of four steps: reading, open coding, integration, and dimensionalization. The first step for analysis is to read all of the transcripts multiple times. The seven interview transcripts for this study were read three times through completely in order to gain a holistic understanding of the data

Next, open coding was conducted, which includes holistically using the data to identify potential categories (Lindlof & Taylor, 2006). For this thesis, open coding helped to identify overarching patterns related to a positive genital herpes status.

Integration elicits the creation of connections between the categories developed through open coding to create themes (Lindlof & Taylor, 2006). It is through integration that separate categories join and become collapsed into more cohesive themes.

Communication Privacy Management and the Disclosure-Decision Making Model emerged during the integration process as a way to make sense of the themes.

The final analysis step is dimensionalization. Dimensionalization includes creating distinct constructs and the ways in which the variations of it are displayed (Lindof & Taylor, 2006). Within this research, four major dimensions were identified. (1) Disclosure occurs as a means to protect the self or partner, obtain emotional support, or retain a sense of closeness ; (2) Barriers to disclosure include fear of stigmatization and a desire to control their private information; (3) individuals who have genital herpes carry certain herpes contradictions when it comes to the seriousness of the virus, levels of acceptance, and levels of reciprocity acceptance ; (4) Individuals with genital herpes have certain recommendations for those who are diagnosed, practitioners who disclose a patient's status, and potential disclosees. Participants' quotations were selected to illustrate the themes using Owen's (1984) criteria: (1) recurrence, where similar meaning is communicated, (2) repetition, which includes the reiteration of key words and phrases, and (3) forcefulness, which takes participants' inflection, volume, and pausing into account. Participant quotations were edited for clarity and vocal fillers were removed.

### **Rigor**

The expectations associated with rigor differ between qualitative and quantitative research. In qualitative research, there is not a focus on the replicability of conditions across contexts (Davies & Dodd, 2002); rather, the purpose is to display qualitative quality (Tracy, 2010). The criteria for quality qualitative research expands qualitative rigor to encompass notions of worthy topics, rich rigor, sincerity, resonance, and significant contributions (Tracy, 2010). It is through these markers that good qualitative research can be evaluated and compared.

Lindlof and Taylor (2006) and Tracy (2010) both indicate the importance of picking a worthy topic within qualitative research. A chosen topic must be “relevant, timely, significant, interesting, or evocative” (Tracy, 2010, p. 840). Considering the rising epidemic of genital herpes, this thesis fulfills all those requirements. Additionally, this thesis will fill gaps in the literature about genital herpes disclosure patterns, which is a consideration Lindlof and Taylor (2006) declared to be important for qualitative research. The origination of this research was from my own problematizing of personal experiences of genital herpes disclosure. Using personal experiences as a point of origin for research allows scholars to best incorporate their careers with their personal lives (Lindolf & Taylor, 2006). Rich rigorous qualitative research promotes the visibility of the data, which includes data collection processes, fitting analysis procedures, and sufficient support for claims (Tracy, 2010). When considering appropriate data collection processes, Tracy (2010) argued one way to ensure rigor is to use an appropriate research sample for the goals of the research where the researcher has spent the necessary time obtaining that sample. For this thesis, the goal was to understand the processes and meanings associated with genital herpes disclosure, as such, only individuals who had genital herpes were consider for the research sample. As discussed previously, the initial call restricted participation to individuals with herpes simplex virus 2; however, it was determined that genital presenting herpes simplex virus 1 should also be considered. Over a month was dedicated to finding participants for this research through the various methods mentioned previously, however, the stigmatizing nature of genital herpes likely impacted research participation. It was determined that moving forward with seven

participants was sufficient due to the qualitative emphasis placed on the quality of the received data over the number of interviews.

Additional data collection considerations for rich rigor are interview and transcription visibility practices including length, questions, details, and accuracy (Davies & Dodd, 2002; Tracy, 2010). The seven interviews conducted resulted in over five hours of data that focused on the interview protocol questions (Appendix B). Through the transcription process, 82 pages were transcribed verbatim, meaning that vocal fillers, pauses, and hesitations were included from all participants. Accuracy of transcription was obtained by re-listening to segments of the interviews to ensure that what was transcribed was reflective of what was stated.

Providing rigor within qualitative research also includes being transparent in the ways that the resulting data is then organized and developed (Tracy, 2010). As such, this chapter provides a detailed explanation of how the data concerning genital herpes disclosure came to be viewed holistically and was then organized and interpreted. Finally, Tracy (2010) stated that practicing rigor in qualitative research includes certifying there is enough support to warrant the claims stated within the research. Within the next chapter of this thesis, extensive evidence in the form of detailed participant quotations about their genital herpes disclosure experiences will be used to support the emergent themes presented.

Qualitative research rigor requires sincerity, developed through the measures of transparency and self-reflexivity concerning the values, bias, and actions that researchers bring to their research (Tracy, 2010). Transparency concerns researchers being honest and open about all parts of the research process, from the measures used to the personal



bias (Tracy, 2010). My thesis demonstrates transparency by being explicit in the methodology used for this thesis from data collection to interpretation. In terms of self-reflexivity, Tracy (2010) posited that the researcher must interrogate their own motivations, biases, and opinions throughout the entire research process from conception to publication. This aspect of rigorous qualitative inquiry reflects the adherence to the qualitative requirement of subjectivity. The origination for this thesis topic was my personal experience with disclosing a genital herpes status. Part of the motivation for the chosen qualitative methodology can be attributed to my desire to make sense and meaning after my positive diagnosis. The purpose of the vignettes at the beginning of each chapter is meant to provide a lens of the experiences that have shaped the ways in I view the data. By doing so in an evocative and aesthetically pleasing manner, I attend to the qualitative rigor marker of resonance (Tracy, 2010). The combination of participant data and vignettes is meant to evoke a sense of empathy within the reader as expected of qualitative research (Tracy, 2010). In the final chapter of the thesis, to account for self-reflexivity as well as transparency, a section is devoted to focusing on my own reflections during the research process.

One of the final markers for rigorous qualitative inquiry is the evaluation of the contribution the research has to the field. Quality qualitative research should make a significant contribution in a theoretical, heuristic, or practical manner (Tracy, 2010). According to Tracy (2010), theoretical contributions “expand, build, and critique” existing knowledge frameworks within the discipline (p. 846). This thesis extends the theoretical assumptions of CPM (Petronio, 2002) and DD-MM (Greene, 2009) in a context that has not been researched extensively. Additionally, certain themes not fully

addressed by the theories or those theoretical elements that could benefit from further investigation can provide interesting potentials for future research, which Tracy (2010) argued is a signification heuristic contribution. Finally, Tracy (2010) indicated that being practically significant means that the research is useful in some meaningful way. The research gathered here has practical implications to provide insight to providers about the methods used to disclose initial genital herpes status to a patient.

The following chapter of this thesis will present the results obtained through the interviews about genital herpes disclosure practices. Each of the four themes were developed from a holistic view of the participant data. Quotations edited for clarity will provide the evidentiary support for the proposed themes. Additionally, the beginning stages of theoretical connections to the CPM and DD-MM frameworks will be addressed.

## CHAPTER 4: RESULTS

*This partner couldn't keep it up as he was too scared of infection*

*This potential partner was too eager to go raw*

*This partner I told too late*

*This partner I never told at all*

*This potential partner kept talking about being nervous as if I was a ticking time bomb*

*This partner used protection and everything was fine*

*This partner I met off a positive genital herpes site and never had to directly disclose, but had one of the worst sexual experiences of my life leaving me crying*

*Wee, wee, wee*

*At home all alone!*

*The manner of telling has never been consistent for me. For some, I've told face to face and others I have waited for the dreaded return text. At times, I've used my status to quickly end a potential romance, a way to prove that they weren't really into me. Usually, my plan works the risks are too great for a quick fling. Whoever you are, whatever you could be isn't valued enough for someone to put themselves at risk. It's not that you're worthless, per say, but that you aren't worth the risk of genital herpes. A very fine line to balance when you're trying to not be crushed by the rejection and remember your own value.*

*It's not to say only rejection has been encountered there have been some who want to continue. While you always hope that someone will get past your infection, it's sometimes a shock when they do. It's hard to believe that someone still wants to be with you despite the risk that any sexual intimacy may hold. These are the moments that you try to remember the next time that you feel disgusted by your body or face another rejection. Partners are out there who want to try and make it work with you, who believe that you and everything you are is more valuable than any potential transmission. That the risk of an incurable infection would never outweigh the benefit of being with you. Those moments are what you grip to when the darkness of your diagnosis rears its head.*

*There have been instances where disclosing has been simple and easy, and ones that are emotionally draining. Afterwards I have felt valued and worthwhile, but also disgusting and slutty. No matter the negative experiences, I still intend to disclose. Despite the positive experiences, it doesn't get easier. It feels like it's always a gamble, but 50/50 odds aren't so bad. The game gets a bit harder though when it's not money on the line, but you, your feelings, your value, your worth.*

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After reading the stories of the participants there were three major themes that emerged when discussing how those with genital herpes disclose their status. It is not surprising that those with genital herpes follow many of the patterns as discussed by Petronio's (2002) CPM theory or Greene's (2009) DD-MM theory. However, the ways in which those with genital herpes perform these theories are unique to their particular circumstances. Moments of disclosure are elicited from those with genital herpes when they are attempting to protect themselves or their partners, desire emotional support, have

significant others who are aware of their situation, or are hoping to maintain certain relationship expectations. It emerged that those with genital herpes are more likely to refrain from disclosure when they are worried about potential stigmatization or have a desire to maintain control of their information. Finally, when it comes to specific aspects of the genital herpes condition there exist significant contradictions that individuals with the virus expressed. Although there are similarities between the previous mentioned theories and other STD research, the findings from this thesis provide an understanding of how those with genital herpes handle disclosure. The following sections will describe each of the main themes found within this thesis using key participant quotes to demonstrate the central ideas.

### **Impetus for Disclosure**

The themes that were garnered through the participant responses have helped to shed light on the gap of research surrounding genital herpes disclosure patterns. Those with genital herpes will disclose their status as a method of protection for self and partner, an imperative response, and to maintain established relationships. Similar to Bickford et al. (2007), the majority of individuals within this research disclosed their status to potential partners. Overall, all but one of the participants had chosen to disclose their status to someone other than the researcher. For each of the participants, choosing to disclose was a significant step in the new reality of living with genital herpes.

**Protection.** Disclosure of a genital herpes status is one method for individuals to protect themselves and potential partners. When individuals are attempting to protect themselves it can be out of concern for their own emotional attachment or a protected self-image. Disclosing a genital herpes status is also a means to protect any potential

partner from unaccepted transmission risk. Whether they are choosing to disclose to protect themselves or others, those with genital herpes are engaging various aspects of the CPM (Petronio, 2002) and the DD-MM (Greene, 2009).

**Self.** While Bickford et al. (2007) found that people with genital herpes refrain from disclosing in order to protect themselves from stigma, this research indicates that disclosing the information is an additional way that a sense of protection of self can be enacted. Choosing to disclose to a potential partner allows a person with genital herpes to protect themselves in two meaningful ways. First, disclosing early allows them to protect themselves from potentially painful emotional attachment. Petronio (2002) indicates that the negotiation between risks and benefits is demonstrative of an inherent vulnerability when disclosing. When controlling the revelation of a genital herpes status, a person with genital herpes is demonstrating this vulnerability. Second, it enables a particular self-image to be upheld within one's own perception. This aligns with the CPM position that personal characteristics influence the ways that boundary linkages are enacted and private information is disclosed (Petronio, 2002).

Within my research, a person with genital herpes often discloses their status early on with a potential romantic partner to prevent emotional attachment. My finding runs counter to the finding that those with genital herpes tend to disclose in more established relationships where they feel safer from stigmatization (Bickford et al., 2007). Those with genital herpes understand that a partner may be unable to accept their diagnosis, in part, to the stigma that surrounds the disease. The participants here indicated that they would prefer to face the potential rejection before emotional attachment has been raised. The concern is that if they were to delay disclosure they would have put emotional effort into

a relationship that will ultimately end in rejection. Jenni, a 20-year-old white woman who has been diagnosed for six months, illustrates this notion by stating, “I’m not gonna put effort into something that is just gonna go away immediately after I disclose to them”. In deciding that the benefit of mitigating wasted emotional effort outweighs the risk of potential rejection or stigmatization, those with genital herpes are choosing their moments of vulnerability (Petronio, 2002). Those with genital herpes are cognizant of the fact that disclosing their positive status could end in rejection and/or stigmatization; however, by disclosing toward the start of a relationship they are able to control their investment into the relationship.

The desire for control of vulnerability and investment is demonstrated through Zari’s, a 21-year-old black woman who has been diagnosed for two years and laughs often throughout the interview, commented, “I don’t wanna take months to tell them and then they’re not okay with me having herpes and then it’s like I just wasted all of my time, and effort into this person”. By attempting to forgo future pain and disappointment those with genital herpes, including myself, often disclose to potential partners early in the conversations. While it has never been the first piece of information that I have revealed to a potential partner, my status is disclosed early in the relationship for the same reasons as cited by my participants. Even though a genital herpes status disclosure happens in longer relationships (Myers et al., 2015), those with genital herpes here are choosing to disclose before those longer relationships develop and the associated emotional attachments occur for fear of increased emotional risk. Participants felt that by waiting to drop the “bomb” of a positive status they are more at risk to get hurt because emotional attachments have already been established. Utilizing early disclosure is an

attempt to protect the experience of vulnerability that those with genital herpes will encounter when discussing their positive status. This finding implies that those with genital herpes would rather encounter rejection from their status from those they have fewer emotional attachments to rather than waiting for stronger emotional attachments to form then disclosing the virus.

Although relationship characteristics may be more impactful when choosing to disclose a positive genital herpes status (Myers et al., 2015), my research contends that there are still important individual aspects to disclosure. A protected self-image can influence the disclosure process of those with genital herpes. This is indicative of the notion where Petronio (2002) found that the creation of boundary linkages occur when an individual has specific perceptions about personal characteristics. When discussing the disclosure of their diagnosis with a partner, those with genital herpes cited perspectives of themselves that influenced why and how it was conducted. Participants who consider themselves to be honest and straightforward indicated that disclosing to partners was important because of that personally held perception. Many participants echoed the sentiment of Aiden, a 31-year-old white woman who has been diagnosed for eight years, “I’m also just, I’m not a liar, I’m a lot of things, but I’m a pretty straightforward person”, she laughed lightheartedly. Others indicated that the consideration of themselves as a “just do it” type of person influenced their inclination to being straightforward when it came to discussing their status. For some, the self-image as being a humorous person influences the ways in which they disclose their status. Those individuals who thought of themselves having a “humorous” personality used those methods to disclose their status to partners. Jenni describes her experience as, “I tried to incorporate some humor into it



cause that's also just my personality". It is easy to understand the participants desire to maintain a levity surrounding disclosing their status, especially when they already consider themselves to be a lighthearted person. From my own experiences, when you are able to add a laugh to the disclosure it makes a difficult situation a little easier to handle. The use of humor as a method for managing boundary linkages for those with genital herpes echoes research conducted by Ebersole & Hernandez (2016) and Smith & Brunner (2016) which indicates that humor is used to for managing other health concerns. By engaging in disclosure, those with genital herpes can reinforce protected self-images, which may be lost if they were to refrain from revealing. Although not directly emergent, it may be important for those with genital herpes to protect certain self-images that support their disclosure process as their sexual self-image is so often disrupted by the awareness of their virus. This means that even though those with genital herpes may have a negative sexual self-image due to their diagnosis, they are still able to draw on other positive self-images, like being a honest or humorous person, in order to alleviate the negative perceptions. The ability to draw on protected self-images enables those with genital herpes to maintain a positive sense of self even when other self-images are disrupted. Yes, their sexual identity may now include genital herpes, but they can still consider themselves an honest or humorous person through the disclosure of this new identity.

Although those with genital herpes engage in disclosure to protect perceived personal characteristics, they also disclose to protect themselves from certain perceptions. None of the participants, including myself, were made aware by their source-partner that they were at risk for transmission. As such, we all expressed frustration and negative

association toward the person responsible for our infection. The lack of perceived safe sex practices by source-partners leaves those who were infected with genital herpes to engage in disclosure that prevents the negative perception we associate with our source-partner. Those with genital herpes disclose so that we are not perceived like our source partner, or as Zari described it her “gifter”, who had been irresponsible or careless. With disclosing we are actively rejecting the actions of the, as Heather, a young 21-year-old white woman who has been diagnosed for three years states, “somebody that did that to me”. By disclosing our status, people with genital herpes are able to protect themselves from the negative image of an irresponsible sexually active adult.

As an asymptomatic genital herpes individual, the only reason I became aware of my positive status was because I was attempting to be a sexually responsible adult by getting tested before adding a new sexual partner. Therefore, it is only through my disclosure that I am able maintain this perceived characteristic as being a responsible sexually active adult. In the few instances where I refrained from disclosure to sexual partners, I felt no better than my own “gifter”. My source-partner never gave me the option to accept the risk and likely did not engage in responsible testing practices. While I may have employed the latter, by not consistently practicing the former I have behaved no better than the partner that brought this on me. The only way that I am able to attempt to save face in these situations is to consistently disclose my status to all potential sexual partners. It is through disclosure that I am able to maintain the perception, for myself and others, as an adult who engages in sexual activity as responsibly as possible.

**Partner.** While people with genital herpes disclose their status for their own protection, they also disclose to protect potential partners. Myers et al. (2015) found

that those with genital herpes disclosed to protect their partner, which was echoed by my participants as a primary concern. Unlike Green et al. (2003) where relationship concerns outweighed transmission concerns in terms of impetus for disclosure, participants here placed emphasis on the risk of transmission. For my participants, disclosing allows them to protect both the physical and emotional wellbeing of their partners.

As mentioned previously, participants were not given the option in choosing to accept the risk of genital herpes transmission. As such, they do not want potential partners to experience the same feelings associated with that transgression. This instance of protection of emotional well-being is illustrated when Zari states:

I don't want somebody to feel robbed of their love life. I don't wanna make anybody feel like how I felt when I first got herpes. I don't want that to happen, I don't want to be the cause of that to happen to anyone else.

Jenni echoes this sentiment when she accounts, "I wouldn't want to do the same thing to somebody else...cause that for somebody else, you know". My experience reflects what Jenni, and the other participants, were explaining when it comes to protecting partners. Even if a potential partner acknowledges and accepts the risk, should they later test positive knowing that you are the cause can be devastating. This fear of putting others through the same ordeal is a major reason why participants decide to disclose their status to partners. When I first contracted the virus the potentiality of putting someone in these contaminated shoes was enough for me to believe that anyone who refrained from disclosing their status was unacceptable and should be ashamed of themselves. Keeping a neutral face when participants did reveal that they concealed their status from partners was difficult. I was confronted by my own biases and judgments

when I later found myself in a situation where I put a partner at risk without giving them the opportunity to accept that risk. While I did feel ashamed, more importantly I realized that it is egotistical to judge someone for an action that you think that you would not do.

*Too often we are proven wrong.*

As such, participants want to save potential partners from the negative feelings that they experienced when they were originally diagnosed, without warning. When participants disclose to potential partners they are, as Carly, a 23 year old white woman who has been diagnosed for four years, states, attempting to “see out for their [partners] best interests”. Most participants discussed that due to the severity of the first outbreak they felt compelled to disclose because they would not want potential partners to unknowingly be exposed or put at unnecessary risk.

Disclosure due to consideration of symptoms, prognosis, and relevance are demonstrative of the assessment of information element discussed within the DD-MM (Greene, 2009). The DD-MM argues that when the visibility of symptoms is high, the certainty of prognosis is high, and the likelihood the condition will impact relevant others is high the more likely an individual will disclose their diagnosis (Greene, 2009). Even though visibility of participant symptoms is not consistent, the experience of initial symptoms was enough to initiate potential partner disclosure. This is expressed when Aiden states, “My first herpes outbreak experience was so awful. I mean, I wouldn’t wish that on my enemy, much less somebody I’m romantically involved with”. My research argues that disclosure for participants is an attempt to protect potential partners from suffering through similar experiences. Participants are fully cognizant of what is at risk for potential partners seen when Heather states:

[Your] literally risking giving them an STD, especially one that they can never get rid of. I wouldn't say it ruined my life, but it definitely destroyed a part of me. I wouldn't want to do that to someone else...I don't want to give that feeling that I had the whole first year of being diagnosed to someone else.

Recognizing that the prognosis of genital herpes is an untreatable, life-long illness, which would impact the lives of potential partners is enough for participants to feel the need to disclose. When participants consider the symptoms, prognosis, and relevant risk to others associated with genital herpes, they disclose to protect their potential partners physical and emotional health.

Although there were no men to compare to in this study, it likely that disclosure done as a measure of protection for potential partners is a very gendered experience for these women participants. All participants identified as women and as such are more likely to be socialized to feel the need to care for and support others within relationships. Hochschild (1989) argued that women are more likely than men to be expected to engage in emotion management and labor, despite the risk or emotional fatigue that can occur in doing so. Most participants were infected by a man who either did not bother to disclose or take responsibility to get tested, however, these women now feel the responsibility to disclose their status to protect potential partners, even when their own protection was neglected. The concern to protect the emotional and physical wellbeing of a potential partner is an emotionally laborious experience and disclosure of a positive status puts a potential relationship at risk and can be emotionally exhausting. However, it is likely that these women feel the responsibility for this endeavor due to the expectation of women to put emphasis on the emotional wellbeing of others.

**Emotional Support.** When it comes to genital herpes disclosure, participants indicated that one of the reasons that they choose to divulge to significant others is the essential need to be able to obtain social support, typically about a medical situation which others are already cognizant. Although participants did not describe disclosure as a “necessary evil”, as found with Kosenko et al. (2012) HPV participants, they did indicate that it was done to obtain social support for their diagnoses. Participants decide to open boundaries and disrupt the privacy surrounding their status to be able to lean on others during a difficult time.

Finding out that you have an incurable, lifelong, and transmittable disease can be a very traumatic event, which Petronio (2002) found can impact disclosure rules. Even if a participant had an established private boundary around their sex life with significant others, those boundary rules changed to help handle the unexpected diagnosis.

Heather described how even though her mother thought that she was still a virgin once she received her diagnosis she said, “I have to tell my mom” in order to find solace. Participants indicated that they felt that they “had to” tell certain significant others, such as family members or friends, because, as Elli, a 24-year-old white woman who has been diagnosed for a year, states, they “need to talk to somebody about this”. For most participants, they did not want, nor feel they were able, to handle the new reality of their lives alone.

The moment that I got off the phone with my disclosing nurse I immediately called my best friend and told her what happened for her to come over to help me deal with this new life reality. Receiving a positive status rocks your world and only through disclosing to significant others are we able to obtain the support that is necessary during

this time. . As Zari states, “When I first found out and I was really distressed about it and I needed someone to talk to about the situation and that’s when I told like my few friends and my cousin”. The choice to disclose to relieve stress about a diagnosis supports Greene’s (2009) idea that preparing for a diagnosis can lead to disclosure to others.

When it comes to genital herpes disclosure, the revealing of a positive status to others occurs to manage the reality of their new condition. Only by disclosing are those with genital herpes, myself included, able to find the support that is imperative to processing this diagnosis.

**Other Awareness.** Additionally, disclosure occurred to participant’s significant others due to the awareness of the participant’s ill health or distraught mood. An aspect of genital herpes is the flu-like symptoms, which the majority of participants experienced. Unknowing the cause, they shared the fact that they were unwell with those relevant significant others to account for their behavior. Once participants found out about their diagnosis they often disclosed at the behest of those significant others continued concerns.

Heather indicated that she disclosed to her suitemates/friends because, “They knew I had been sick and that I was worried about something”. Other participants spoke about how they had to provide an explanation to significant others because of the known doctor’s visits and illness, like Jenni who disclosed after her sister’s constant questions of, “What is it? What did the doctor say?”. For participants, disclosure did not only occur after questions of ill health, but after others perceived a shift in mood. This pattern was seen in statements like Zari’s when she disclosed to a friend because, “I told her a few weeks later because she was still wondering why I was so sad that one day [her day of

diagnosis] and I was like, ‘Well, because I have herpes’”, she laughs slightly. This aligns with Petronio’s (2002) claim that boundary linkages are not at the sole discretion of the individual, but that others can attempt to create them through the inquiry of private information. For these participants, boundary linkages were created from their significant other’s interest in their health and wellbeing.

Although many participants disclose based on their own desires to let another know about their current situation, others are backed into disclosure. While participants could have refused to disclose or lied about their results within my research they chose to remain open and honest about their condition. It is unclear if these participants would have disclosed their situation without the prodding of a significant other, regardless they still disclosed when they were asked.

**Closeness.** Catona et al. (2016) and Greene (2009) found disclosure is likely to occur when an individual perceives their relationship with another to be close or highly valued. My research supports these findings as participants indicated that they disclose to significant others as part of an established relationship. Participants felt that the current closeness of that relationship meant that they needed to discuss their status with that person. By choosing to disclose participants are not only maintaining their perception of the relationship, but also reconfirming held boundary beliefs.

Many participants indicated that the reason that they disclosed their status was so that they did not have to “hide” or “keep secrets” from the significant others in their lives. As Jenni states:



It's just nice to feel like I'm not hiding things from my best friends or family members. I tell people I'm going to be around the most, so I can just not have to, like, tiptoe around the subject or lie about things. I don't know, it's just nice to be open and just not have any secrets.

Often, participants felt that it would be a burden to keep it hidden and that it would be easier for them to explain their behavior openly and honestly. Aiden stated that telling a partner is easier than having to create, "bumbling excuses about why I wouldn't want to have certain sexual acts, right, it gets so complicated". By revealing this private information, participants showcase that refraining from boundary linkage about the topic is not worth the inconvenience it would cost to maintain. They would rather be able to talk about it freely by creating a collective boundary over keeping a private boundary. This seems to be in opposition to Nichols (2012) finding that individuals refrain from disclosure of their sexual history in order to control what they perceive to be private information. For those with genital herpes, controlling the private information or maintaining a private boundary about their status is not always the most important consideration, but that the convenience of a collective boundary is more desirable within certain relationships.

Additionally, participants felt that the relationship itself called for the disclosure of the information. When discussing why they disclose their status, participants revealed that it was due to the type of relationship that they had with a significant other. For example, Heather stated, "[I told] my best friend from home I told her just because she's my best friend. I can't not tell her this". To maintain a perception about a relationship then it requires the disclosure of certain information. In this instance, for Heather, her

“best friend” relationship contains certain boundary rules that must be maintained to uphold that perception. This notion of boundary rules based on the relationship with a significant other were further seen when participants described disclosing based on the “closeness” of a relationship. As in when Carly disclosed to “some of my really close friends” or Jenni “told my sisters because I’m closest to them”.

Many of my participants indicated that they told their mothers because they had a close relationship with them. While I can understand how an idea of closeness is likely to elicit disclosure, it has in some of my relationships, it has not within my own relationship with my mother. As of this writing, neither of my parent are aware of my diagnosis and even though I think about telling them often I have no plans to do so. Yet, I would still consider myself close with both of my parents, especially with mom. It is an uncomfortable moment when participants described how their closeness with their parents brought about disclosure and yet, for me, it has kept me silent, it can make you question your own relationships. Whether it was a friend, sibling, or parent participants cited being “close” with them as a reason for disclosure.. The expression of disclosing based on closeness is indicative of Petronio’s (2002) finding that boundary rules are established through the selection of confidants, specifically the shared intimacy level of the relationship.

An aspect of disclosing a genital herpes status is the ability to maintain established relationship with significant others. In some instances, disclosure is used by participants to preserve a relationship where they do not have to hide facets of themselves. For others, it is about sustaining the boundary rules associated with their perceptions of a close

relationship. Overall, the relationship status between significant others and a person with genital herpes influences instances of disclosure. Why is this important to know?

### **Boundary Barriers.**

When participants conceal their genital herpes status they are practicing a management technique in their right to control private information, as described by Petronio (2002). Determining who is restricted from their private status requires participants to engage with the decision-making process. For these participants, one of the primary factors in the choice of not disclosing is the anticipated negative response from a recipient. This aligns with Greene's (2009) DD-MM which contends that should an individual expect a negative reaction to their information the likelihood of disclosure decreases. Knowing that those with genital herpes are highly stigmatized, when participants were uncertain about others' reaction they chose to conceal to prevent the negative association. Additionally, to maintain the privacy surrounding their status participants enacted boundaries based on their perceptions of appropriate topic rules and expectations of boundary turbulence. Regardless of the motivating factor, the participant's concealment of a genital herpes status is an act of choosing a personal boundary over a collective one.

**Fear of Stigma.** As found with Bickford et al. (2007), those with genital herpes refrain from disclosing their genital herpes status due to the fear of stigmatization, however, this fear is not limited to potential partners. Participants in this study indicated that they chose not to tell friends, parents, or partners due to concern about how they will be viewed. As mentioned by Petronio (2002), any act of disclosure places an individual in a moment of vulnerability. This moment is impacted by the response of the disclosure

recipient. For those with genital herpes, they fear that revealing a positive status would leave them vulnerable to the stigma of the virus.

Should they divulge a positive herpes status, participants explained that they would be thought of as a “slut” or “whore” and be viewed as “disgusting” or “irresponsible”. These stigmatized feelings seen in comments like Elli’s, “People think that you’re dirty and a slut and that you fucked up and they just won’t get over it and it becomes a tidbit of gossip” and Helen’s, a 36-year-old white woman who has been diagnosed for four years, short response of “I don’t want people to think I’m a slut”. Although everyone spoke about the fear of being labelled promiscuous, hers was the most heartbreaking for me as she was the only participant who has never been able to disclose her status to another person. As to my knowledge, I am the only person who knows that she has genital herpes and I don’t even know her. She was the only person whose interview made me cry because I couldn’t have imagined going through this experience entirely alone. The moment I was done with her interview I hugged my best friend who was there for me when I first found out about my diagnosis. It’s for the Helens of the world that this research is extremely important, especially as a means to help destigmatize the infection.

Due to the sexual nature of the virus, consistently, participants feared that they would be judged for engaging in sexual acts that may or may not have occurred. Petronio (2002) argued that privacy rules are often established through cultural expectations. Within a culture that vilifies the sexual expression of women and views STD as a punishment for those actions, it is understandable why participants utilize a rule that prohibits disclosure. Zari expressed this sentiment with, “I feel like herpes is like, the

mark of the whore, and society just really, with all the slut shaming and stuff that's going on, they just really make it out to seem like if you have an STD you're sleeping around and you're doing all this. It can just, it could just be a mistake". Similarly, Heather concealed her status because she didn't, "Want someone looking at you like you are dirt. Um, there's just that stereotype that people with STD are whores and like, they've been with so many people, and that's not always the situation". Although not explicitly stated by most participants, the fear from the potential stigmatization from others is intensified as it echoes the thoughts that you cannot help but think about yourself when you're diagnosed.

I fear the stigmatization from others because I have already had those thoughts about myself. You are plagued by the notion that you are dirty or slutty or somehow deserve to have this virus. It is not just the fear of some random other's opinion, but the reinforcement of your already negative self-perception. Regardless of the actual situation or the fact that none of us were given the option to accept the risk of transmission, it is difficult to not repeat back internally the slut-shaming behavior of society at large. Again, this seems to be a very gendered experience as the terms of "slut" or "whore" are more typically lobbed at women over men. It is women who are often seen as morally lose when they engage in sexual activities over their male counterparts. This becomes especially interesting when paired with the fact that the majority of these women were infected by their men partners, who likely would not experience the same type of naming should they disclose their status.

Due to this constant fear of a stigmatized and negative reaction, when participants were uncertain of a recipient's response they erred on the side of concealment. As

Heather states, “You also just don’t know how someone is going to react to it”. Many participants echoed the sentiment, almost identically, indicating that the response uncertainty was not worth the risk, especially when the potential response could be so emotionally devastating. The risk of potential judgment and stigmatization prevents those with genital herpes from disclosing their status to others. The fear associated with disclosure means that those with genital herpes are either unable to form sexual relationships or they engage in sexual relationships without disclosing their status. Additionally, not being able to confide a status to others means that those with genital herpes are unable to obtain often necessary emotional support during the difficult diagnosis process.

**Controlling Information.** The moment that a person makes the decision to refrain from revealing their genital herpes status to a specific individual they have created, what Petronio (2002) calls, a personal boundary. By justifying the decisions about others awareness of their status, participants showcase Petronio’s (2002) third supposition, demonstrating that boundaries are made based on the idea that those with genital herpes own the right to control others knowledge of this information. One way in which participants enacted this control is through establishing a boundary linkage rule, specifically by focusing on topic appropriateness (Petronio, 2002). Another demonstration of the expectation of control is through participants concern over boundary ownership and expected turbulence. In setting conditions for collective boundaries, participants reinforce their right to maintain privacy.

A personal boundary becomes a collective boundary only if a boundary linkage is allowed to be formed between two individuals (Petronio, 2002). Participants prohibited a

boundary linkage about their status whenever they made the decision to conceal their genital herpes diagnosis. For some of the participants, the exclusion of this boundary linkage within a given relationship was based on rules encompassing whether the type of information was allowable for that particular dynamic, which Petronio (2002) calls topic selection. Aiden, whose infectious personality adds to her gender nonconforming style, explained that she never disclosed her status because, for her, it was “Not something that’s regularly talked about amongst friends”. Within certain relationship dynamics, participants indicated that there was a restriction of the type of information that was shared between them. Heather mentions that she refrains from the subject with certain friends because it is not something that they “need to know”. When it comes to boundary linkage rules, participants create boundaries based on the understanding that there are certain rules about the types of topics that are discussed. This is reflected even in families, as Jenni describes why she concealed her status from her father, “I don’t really have a lot of serious conversations with my dad, , I don’t know, just not something we talk about”. Considering the sexual nature of the virus it is understandable how participants may not want to discuss their sexual exploits with their parents. I never want to talk about my parents being together and similarly I never talk about my own sexual life with them, especially the fact that I now have a sexually transmitted infection. Avoiding the topic of sexual health, aligns the findings from Ebersole and Hernandez (2016) arguing that families manage boundaries by avoiding certain health topics. Held rules about topic selection enable participants to control boundary linkages prohibiting the establishment of collective boundaries with certain individuals about their status.

One of the reasons participants made the decisions to conceal their status was due to the concern that once told, the information would be outside of their control. Whenever a boundary linkage is made and a personal boundary becomes a collective one, the information that is shared is now considered co-owned, whether the disclosing individual wants it to be or not (Petronio, 2002). Should they release control, participants feared that their private information would spread outside of the collective boundary that they originally established, which echoes other non-disclosure research (Greene & Faulkner, 2002; Green et al., 2003; Newton & McCabe, 2008a). Elli illustrates this concern for private information spread when speaks about why she concealed her status from a potential partner, “when [his] friends start to ask about me, I don’t want him to go back and say, ‘Oh, she had herpes’, she follows up with, “this guy knows so many of my coworkers, like, if this gets out at work, like, that’s not good”. The distress participants have about the potential for their status to be spread to undesired others is indicative of the expectation of control and ownership surrounding private information even after it has been collectively shared with another.

Although any act of revelation or concealment has associated vulnerability, due to the stigmatizing nature of genital herpes, as discussed previously, feelings of vulnerability are compounded for participants. As Elli states, “It has such a horrible negative stigma that I cannot have people with whom I’m trying to be professional know something like that about me”.

It was interesting in this moment to see our different perspectives of professionalism. In writing this thesis I am actively using my positive genital herpes status, and its associated research, to claim my professionalism. When it gets accepted it



will be published online and any future employers will be able to access the information becoming aware of my status whether I want them to or not. Once I have completed this thesis my status will, at least partially, be out of my control and yet is meant to add to my own experiences of professionalism.

Non-disclosure arises when participants are uncertain about whether the recipient of the information will respect the indirect collective boundary marker.

Jennidemonstrates this consideration for respect of boundaries when she restricts her status from new partners because, “They don’t have loyalty to you yet”. For Octavia, and other participants, they will not disclose unless there is a level of certainty about if a recipient is going to cause boundary turbulence. If an intended recipient is expected to cause boundary turbulence, a moment where boundary coordination is disrupted (Petronio, 2002), then a participant will withhold disclosure of their status. As Zari explains, a condition for disclosure is determining if “they’ll like say something about it to other people”, should participants feel that another might share their private status, expanding a collective boundary in an undesired way, participants will largely continue to restrict access to the information.

### **Dialectical Tensions**

The research reveals an interesting phenomenon when it comes to exploring the expectations of those with genital herpes during their disclosures. Petronio (2002) indicates that there exists a dialectical tension between privacy and disclosure, however, this sense of push and pull between two competing ideals is not the only tension that exists for those with genital herpes. Individuals with genital herpes have major contradictions when regarding the seriousness of the virus, the perception of others who

accept the news, and whether they would accept the virus themselves. Below excerpts from my participants are used to explain each genital herpes tension further.

**Seriousness Inconsequential.** When it comes to describing the experience of the physical symptoms of the genital herpes virus, all of the participants spoke to how extremely painful the outbreaks felt. The individuals indicated that the sores were terrible and most suffered from flu-like symptoms. Aiden described her first outbreak as, “I had a crazy fever, I have terrible sores, you know, it’s just, it was horrible”. For her, the pain around her first outbreak was almost unbearable. Similarly, Heather described hers as being, “by far the worse pain I have ever ever had at that point in my life”. For both of these participants, as well as many others who echoed the same sentiment, initial genital herpes outbreaks were some of the worse pain that they had experienced in their lives. These were moments that I was unable to relate to my participants, they all had experienced these massively painful outbreaks, but I was asymptomatic. I have no idea what it is like to have to handle these outbreaks or the repercussions of them. As nice as it is to not experience any painful symptoms, it also feels as if I missed out on the reality of the virus. For those participants who had to suffer through the genital herpes outbreaks they have concrete experiences that solidified their diagnosis. They felt ill and were positively diagnosed as having genital herpes. I never had symptoms so coming to terms with my diagnosis was difficult because I never felt sick. Being told that you have an invisible incurable virus that you may never experience, but that any potential sexual partner could suffer from is a tough pill to swallow. It is interesting to note then, that although indicated as the worse pain to experience, some participants with genital herpes ultimately described having the virus as not being that bad. Zari states that genital

herpes “isn’t that big of a thing”, while Elli relates similarly that “it’s really not that bad”. The frequency and intensity of a genital herpes outbreak reduces over time, as such, individuals with genital herpes seem to believe that although they experienced excruciating pain, it was not enough for them to categorize their experience of having genital herpes as the worst thing that could happen to them. In this I, can relate, as I have never had to worry about physical symptoms and it is as if I am a completely healthy woman. For me then, especially, having genital herpes is not that bad of a situation. If this virus was not transmitted sexually having the condition would have no impact on my life. Overall, after the initial outbreaks, having genital herpes became, for most of my participants, a minor aspect of their lives. These opposite experiences, however, speak to a sense of contradiction that those with genital herpes seem to express. It is important to understand that not all those with genital herpes have the same experience and that there exists a tension between the feelings from the initial outbreak and later acknowledgement of the impact on their life.

### **Acceptance-Dissension.**

Another set of contrasting tensions that those with genital herpes seems to share surrounds the level of comfortability that they have with others who may learn about their status. The majority of the participants indicated some level of desire to be able to freely express their status without fear of stigmatization, as discussed previously, or judgment. My participants indicated they would hope their potential partners would, as Jenni states, “keep an open mind” when learning about their status. In doing so, potential partners help mitigate the negative feelings that those with genital herpes may experience when disclosing. Other participants indicated that they wished that disclosing that they had

genital herpes was less of a big deal. Elli states, “I just want to be able to tell somebody, ‘Yes, I have herpes.’”. It is through this statement and those that carry the same meaning, that individuals with genital herpes show their desire for those who learn about their status to create a welcoming, or at the very least, open environment to have the conversation.

However, this level of acceptance and openness is only meant to go so far, according to the perspective of many individuals with genital herpes. While they want to be made comfortable when disclosing to partners, should that comfort seem like too much acceptance individuals with genital herpes begin to question the status and actions of the potential partner. For example, Carly discussed how she felt with a partner who seemed completely at ease with the potential risk of infection, “Like the one guy who didn’t really care at all. I was like, ‘Where’ve you been? Are you dirty or something like that, why don’t you care? Is there something wrong with you because you don’t care as much as you don’t?’” Carly. By being too accepting of a genital herpes status, a potential partner is putting themselves at risk of undesirability. Additionally, this puts the potential partner’s STI status in question. Zari used the level of partner acceptance as a warning for others:

But when you disclose to people, some people who were justway too quick and too willing to accept the herpes, they might have herpes, they might have something else because if they just don’t care about it, at all. If they, maybe if they give you a really good thoughtful response and okay, they might just be a good person. But if they’re just like, ‘Oh, whatever’ they might have something, and they might be okay with it because they’re just trying to hook up with you.

There is a fear that should a potential partner seem too eager or accepting of the positive genital herpes status, they are attempting to hide or conceal something about their own STI status. As mentioned, it is also a way to gain perspective on the intentions of the potential partner as merely looking for sex. Participant were then torn between their desire to be accepted for their status and the degree of that acceptance. Again, this indicates a sense of contradiction surrounding their genital herpes experience.

### **Advocacy-Opposition.**

As discussed above those with genital herpes have a desire to be accepted for their status. Those with genital herpes would like to be able to disclose their status without fear of stigmatization and to have others be open to their condition. It is interesting to note then the contradictory nature of a potential reversed situation. Those who currently have genital herpes expressed that if they were told about a potential partner's status, and they did not have the virus, they would likely not be open to continuing or having a sexual relationship with the person. Zari indicates that, "If I would have been told by my gifter, that he had herpes, I probably wouldn't have messed with him cuz I don't wanna have herpes". The desire to be free of the condition is coupled with the desire to avoid exposure to the virus by any potential partner. Elli continues, "Yeah, I mean I know it would have been a deal breaker for me". Although individuals with genital herpes would like others to be accepting of their status, many showed that they would not be open to extending the same to others should the situation be reversed.

It is important to note, however, that those with genital herpes are aware of the dissonance between these two ideas. They are not disillusioned to the fact that their lack of desire to be involved with someone with genital herpes is inherently contradictory.

This contradictory aspect, however, enables them to be a bit more understanding of those who may not want to consider a relationship with them. This is expressed through Zari's statement of:

But usually, usually I don't care, because if I was in the other's shoes, if I was on the other side of the table I probably wouldn't be okay with it. So, I mean, I know that's so hypocritical cause I have it now and I want people to be okay with it. But, if I didn't have it and someone was like, 'Oh, I have herpes.' I'd probably be like, 'Oh, thanks for telling me that, but it's just not what I'm looking for at the moment'.

Those with genital herpes recognize the tension between their desire for others to be accepting and their own unaccepting behavior should they have been given the opportunity of a choice. Additionally, they understand that this mindset only perpetuates the stigmatizing aspect of the virus caused by an ignorance of the condition. This sentiment can be seen in Carly's comment of, "I think that if somebody were to tell me that they had it I don't think I would be into them because it is a lifelong thing, but then again, I also see the ignorance in that because I know how many people actually have it" Carly. Even though those with genital herpes understand the commonality of the virus, along with other important aspects, they cannot seem to distance themselves from the desire to never be exposed. This is another way in which those with genital herpes express a tension surrounding their status. It is important to note this tension to understand how those with genital herpes advocate for their own acceptance, while also opposing the cause for their push for acceptance.

Through my participant's stories and my own experiences, we can see three major themes that emerged when understanding the disclosure process of those with genital herpes. First, we see how there are certain impetuses for disclosure including the protection of the self and potential partners, the desire for emotional support, the awareness of significant others, and the expectations held within certain relationships. Second, there exist certain barriers to disclosure of a genital herpes status such as a fear of stigmatization and the desire to control personal information. Finally, through my participants stories we see the dialectical tensions that emerge through the disclosure process of genital herpes. Through Petronio's theory of CPM we see how those with genital herpes control their private information by limiting the topics discussed with significant others and through their concern for boundary turbulence should a confidant divulge their status to others. Additionally, CPM provides a framework to understanding how weighing of risks to benefits, personal characteristics, and the quest for boundary linkages by others influence the disclosure patterns of those with genital herpes. From the perspective of the DDMM, those with genital herpes are heavily influenced by assessing particular information aspects of the virus and the anticipated response of recipients. However, it is important to note that while CPM and DD-MM provide excellent frameworks for understanding genital herpes disclosure, it does not take into consideration the specific patterns associated to those with genital herpes. This research is important as it pushes our understanding of how those with genital herpes engage with the disclosure process. Additionally, it is only through exploring genital herpes disclosure that we will be able to encourage future disclosure, establish practices to assist in disclosure, and begin to destigmatize the perceptions surrounding the virus.

## CHAPTER 5: PRACTICAL APPLICATIONS

*When he kissed me my body moved in uncontrollable ways. A stomach turned acrobat somersaulting and bouncing backflips. A heart with sprouted wings bursting from captivity. Freshly made jello knees left wobbling. Had me thinking in terms of “golly” and “wowzers” and “damn, I can’t wait to see him naked”. Because that was the plan, I wanted more than anything to sleep with this man, but I couldn’t, at least, not yet.*

*“You know it is the third date,” he whispers as he kisses up my neck and his hands trail to places that makes his desires well-known.*

*Eyelids flutter as I move his hands to less tempting places, “Yeah, I know and I definitely want to, but, um, well, we haven’t even, you know, like, talked about things, um, like, our sexual histories or preferences. I mean, when was the last time you got tested?”*

*“I’m clean,” he laughs.*

*“Oh, so it’s been recent then? Like, have you had many partners since you last got tested or...”*

*His frustration is palatable, “A few, but we used protection so...”*

*“Oh, cool, um, well, I haven’t gotten tested recently, so I’d rather, you know, wait until my results come back, not like I’ve had anything concerning or something, just, you know, to be safe.”*

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*“Are you sure you want the full spectrum testing?”*



*“Uh, yeah, I’m sure,” I don’t understand why I have to convince the nurse practitioner to give me a full STI screening. Shouldn’t she be encouraging responsible sexual behavior, especially on a college campus? As someone who is studying sexual health and sex positivity I am constantly speaking about how important it is to engage in safe sex practices. How could I not get full testing before adding a new sexual partner? I’d feel like a fraud and a hypocrite. If I’m going to speak about it, I feel morally obligated to practice it as well. So here I was, demanding a full spectrum test in order to get the green light to funky town.*

*“You haven’t had any symptoms or anything, right?”*

*“Well no, but I just want to be safe.”*

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*Ring.*

*A simple phone call has turned into a piercing alarm, simultaneously obtaining my attention and telling me to run away from it. An unknown local number. It could be anyone, I cerebrally argue. But the knots in my stomach that have made a cushion for my heart knows better.*

*“Hello.”*

*“Hi, is this Katrina?”*

*If only I could be someone else, “Yes.”*

*“Hi, this is Peggy, from the health center. Are you able to talk?”*

*“Sure.”*

*“So, your test results came back, and I’m sorry but you’ve come back positive for HSV-2 or as it’s more commonly known, genital herpes,” Peggy is entirely too nonchalant about this information. The world is crashing down around my ears and it’s as if she just told me I had a cold, not an incurable sexually transmitted infection.*

*“Wait, are you sure? I mean I’ve never had any symptoms or anything. I don’t understand,” I say, pulling the covers closer around a suddenly vulnerable body.*

*“I know, but the virus can be asymptomatic meaning that people can have it without ever showing signs.”*

*“Oh, um, okay, so what do I do? Isn’t there some type of pill or something?”*

*“Well, since you don’t have any symptoms the pill won’t really do anything for you. It’s really only for those who have outbreaks.”*

*“There’s nothing I can do? But, how do I...I mean...what does...what do I do?”*

*“Unfortunately not, it’s just something that you’ll have to live with, if you have any other questions you can send us an email.”*

*The click of the line the apparent end of the conversation. Five minutes, it only took five minutes for her to turn my world upside down and leave me drowning where I was once on solid ground. I was given no recourse, no recommendations, no sources for support. Couldn’t she at least have provided some type of life raft? I know genital herpes doesn’t kill you, but I’m pretty sure this is what dying feels like.*

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An important aspect of research is the practical applications that can be delivered once the project has been completed. For me, practical application encompasses any information that could be provided to the public that would be beneficial to the targeted group. With this research that means information that can make the experience of a positive genital herpes diagnosis or disclosure a little bit easier to handle. This section provides essential information about genital herpes for those who are recently diagnosed, may provide a positive diagnosis, or bear witness to a disclosure. The recommendations contained within the chapter are practical methods that can be distributed to all the aforementioned parties as a resource. Whether through a website, media campaign, pamphlet, or just general reading all the below information can be used to facilitate a potentially easier experience for those with genital herpes. Not only would this distributed information directly help those recently diagnosed, but it could make their interactions with health practitioners and disclosure recipients more supportive. Positive interactions with health practitioners becomes especially important when paired with the Ports et al. (2013) findings that demonstrate how practitioner's communication with genital herpes patients impacts their quality of life and future prevention behaviors.

**Recently Diagnosed.** My thesis participants expressed words of encouragement for others who might have recently been diagnosed with the virus. Many participants wanted to remind the recently diagnosed that they weren't alone in their condition and that life could continue, albeit a little differently, after they had been told of their status. Aiden stated that, "Although herpes is something that you have for life, it is not a life sentence, right". It is heartening to hear from someone who has carried the virus longer than I have to admit that it has not been the end of their romantic life, which is a major

fear to those recently diagnosed. There was on overall indication that participants wanted the recently diagnosed to recognize that their life was not over because of their status and they could find someone to love them despite the virus. While trying to be hopeful, they also cautioned the recently diagnosed that they may experience moments where someone is not accepting of their status, but that it was normal and just meant that the search for a relationship would continue. The whole, “it will be okay” mentality is expressed when Jenni argues:

It’s totally up to the other person and if they, you know, if they genuinely care about you and want to be with you then it’ll work out and it’ll be fine, and if not, if that’s, a deal breaker for them entirely then it just wasn’t meant to be between you two.

The need to cushion the experience of potential negative reactions was articulated by most of the participants. The potential of a negative reaction was coupled with the hope that the recently diagnosed would not let it affect their sense of personal value and worth, like when Heather states:

Don’t let it make you feel like you’re worthless and that your life is over...people out there who are accepting of it and want to learn more about it and how, how a relationship is gonna move on from there. But also, don’t let the people who react poorly to it really make a big dent in your heart. It’s disappointing when someone gives you a bad reaction. But it’s like they say, there’s a bunch of fish in the sea, and there’s good people out there.

My participants were constantly trying to remind those who might recently be diagnosed that they are still valuable people who are worthy of love and affection. There seemed to be a need for them to remind others that they were not disgusting or that having genital herpes was, as Zari indicates, “something that, something about you that is just like repugnant”. Throughout the duration of this research I have had potential partners who have been willing to take the risk and others who have made me feel disgusting for having the infection. However, it has partially been through my interactions with these women that I am able to remind myself that even if I have a less than courteous partner my worth is not diminished. I am still a valuable person and partner. My participants in this study gave recommendations that would help to remind recently diagnosed individuals that their lives could continue after exposure, which included positive views of the self and the potentiality for romantic relationships. It is desperately important that those who are recently diagnosed are given these types of messages from their initial awareness of their infection. While most of my participants were able to obtain this type of supportive mentality, there was one who did not have access to this type of information who consistently felt isolated, alone, and worthless. This is why it is imperative that disclosing practitioners provide those who are recently diagnosed with support systems and resources, which unfortunately none of my participants experienced.

**Practitioner.** The majority of participants indicated that their experience with the health practitioner who disclosed their status left plenty to be desired. They felt that they were not supported and thrown a curveball that the practitioner did not help them catch. Some participants wished that the practitioner would have given them advice on how to

disclose their status to others, Helen wishing that, “I had been told what to do, what to say, instead of just being told and kind of being left out in the dark to make my own decision”. My participants, including myself, do not think we were provided the necessary tactics that would allow us to have the difficult conversation of risk with any potential partners. Additionally, practitioners never provided any substantial resources for us to find the emotional support that was needed after receiving the diagnosis. It would not be difficult for practitioners to find reputable resources that could help participants with processing their condition. Even a pamphlet that discussed next steps after diagnosis, including methods to disclose to past or future partners and resources to find further support/information would be more beneficial than leaving those who just found out that they have an incurable infection floundering for themselves.

Not only did my participants feel that practitioners provided insufficient disclosing resources, but that practitioners didn’t provide enough emotional space for what was, for them, a very gut-wrenching experience. Additionally, most participants wish that practitioners had provided more basic information about the virus, including what to expect with symptoms, frequency of outbreaks, the commonality of the virus, and risks of transmission. Heather expressed the desire for the practitioner to:

Have sat there with me for a few minutes and let me process it and then maybe come up with a few questions. I wish she would have told me what the next step was going to be or what’s gonna happen in the next few days.

Individuals who have just recently been diagnosed with genital herpes are often unfamiliar with the various facts about the virus, and are looking for their practitioner to help guide them in the right direction for the appropriate information. Aiden states:

I wish that they would have said something along the lines of this will complicate a lot, some of your relationships, but it's not a lifetime sentence to loneliness...I wish that they would have told me how common it was so that way I didn't feel like I was all alone...I wish someone would have told me that, not that it's okay, I wish they would have just said, 'Yeah, it's gonna be hard, but you're not alone'.

This space for information is felt by most participants to be unfilled by their disclosing practitioners who seem to have a nonchalant attitude about the diagnosis. The exception to this negative perception of a casual attitude was expressed by Zari who indicated that it was beneficial because it helped them to realize that having the virus really wasn't that big of an issue and that it was not the end of their lives. Even still, most individuals who have recently been told that they have genital herpes would have preferred a little more support from the disclosing practitioner, because although the virus may be common, it is still a life changing experience.

Health practitioners who may find themselves diagnosing a positive genital herpes status should be aware of the impact that their actions can have on the individual. First, health practitioners need to be cognizant of their own reactions. Although, they may have encountered many genital herpes diagnoses before this patient and will likely experience more later on they need to understand that this is often a life-changing experience for those recently diagnosed. Having a calm attitude is beneficial to maintaining the fact that genital herpes is livable, however, practitioners need to ensure that their reaction does not come off as too nonchalant as it reads as uncaring. Second, practitioners need to understand that those who are recently diagnosed are likely unaware of the specific information about genital herpes. When they disclose a positive status to a patient, the

patient probably has little or no knowledge about the virus, including transmission facts, preventative measures, places to find emotional support, future disclosure practices, or even others who have had the infection. It is likely that the only references that a patient has are from the media, which often casts genital herpes as the butt of a rude joke or one of the most disgusting things that could happen to a person. Health practitioners need to either be able to directly provide the necessary information or have at hand resources that can help the patient obtain the information on their own. We would never expect patients of other life-long ailments, like HIV/AIDS, to hunt for information on their own, so it shouldn't be left on the shoulders of genital herpes patients either. Yes, it may seem to be a bit dramatic to liken genital herpes to HIV/AIDS, however, in both instances patients are given a diagnosis that completely disrupts their lives. This leads to the third expectation of practitioners, leave emotional space for patients to process their diagnosis. Often this revelation is unexpected and extremely painful, by taking just a little more time with a patient, practitioners can provide initial emotional support for patients who are in crisis. Additionally, it gives patients the time to develop important questions or address relevant concerns with practitioners. By demonstrating these three components health practitioners would be better able to serve their patients who have recently been diagnosed with genital herpes.

**Other's Reactions.** Finally, those with genital herpes had specific recommendations that they wished others would keep in mind should they ever be a part of this type of disclosure as a potential partner. Largely, as mentioned previously, those with genital herpes would hope that any potential partner would keep an open mind when learning about the diagnosis. This did not mean that individuals with genital herpes



expected those without to be immediately accepting of the potential risk, but that they would take the time to listen. They encouraged people to engage with the disclosing partner by asking questions to learn about the virus and potential risk. Additionally, they would want potential partners to refrain from stigmatizing them or placing derogatory names on them or their actions. They want potential disclosing partners to realize that, as Zari indicates, “it’s not this scarlet letter they make it out to be”. By refraining from these actions potential partners can help individuals with genital herpes to become more comfortable with disclosing. Although an extensive quote, the following statement from Jenni best represents how the reactions from a potential partner can greatly influence the lives of those who attempt to disclose:

I don’t know, keep an open mind, even if you don’t know the person very well they’re still a human being and things that you say to people, people remember that and they’ll carry it with them and if you react poorly to somebody when they disclose to you, it’s going to discourage them from wanting to [disclose]. I’m not saying you have to stay with the person, but there’s ways to go about it and be like, ‘You know, I’m not really comfortable with this, I need some time, or it’s not for me’. Then if you just have a really dramatic reaction and it would just discourage the person from wanting to tell anybody ever again. So, either they’re going to go around and possibly spread the virus and more people are going to end up with it or they’re just going to feel like they can never date again and never have somebody and that’s, you know, devastating.

Those with genital herpes understand the impact that a negative response can have on a person attempting to disclose their status to another person. Whether it is the first

time or the fiftieth time of disclosing having an extremely negative response can cause detrimental impacts to those with genital herpes. I have had largely positive disclosing experiences, however, every time that a negative one comes along it still has the potential to drop me into a deep depression that leaves me questioning if I ever want to date again. Therefore, not only can negative reactions influence current relationships, but it can have a ripple effect against any future potential partner disclosures or relationships. Individuals with genital herpes acknowledge that not every person they disclose to will accept the risk of transmission, but they do hope that they would at least be willing to listen and engage in a conversation.

From the stories of my participants it's important that certain concepts are provided not only to those who are recently diagnosed, but those who may give a diagnosis or receive a disclosure. First, those who have been recently diagnosed should remember that this is not the end of their love life, try not to let negative reactions damper your spirits, and you are still worthy of love and value. Second, health practitioners need to be cognizant of their delivery of a diagnosis, the importance of the information they provide, and the need for emotional space for patients to process. Third, people who may be a recipient of a disclosure should try to remain calm, be open to having a conversation, and recognize their reactions can greatly impact the discloser. It is through the distribution of these practical application that those with genital herpes may be able to experience a smoother transition to living with and disclosing their positive status.

## CHAPTER 6: DISCUSSION

*“Sorry,” I whisper sliding breathlessly into a seat that should have had my behind in it a half hour ago. I pick up pieces of the conversation indicating that we are talking about our seminar papers...great.*

*“Katrina, everyone else has already spoken about what they have settled on for the paper. What about you?”*

*Eyes once crusted with sleep spring open and though I thought I excavated my throat, apparently enough roots remained. Easing around them, “Well, I’m doing personal vignettes for my thesis.”*

*She prods, “Yes, but what are you doing it on?”*

*My body vibrates, a motion censored warning system. Danger Will Robinson! Danger! Danger! Sluggish eyelids attempting to give time in order to comprehend why she couldn’t remember. We were in her office. I can recall the exact position of our bodies, the words that were tumbled, her face as I disclosed. Is she doing this on purpose? Trying to force my disclosure so that I can actually write about it? Okay, I get it, but damn, I don’t want to talk about this right now. The benign white cement walls of the classroom become reflectors of the humming fluorescents. My normal spotlight glow perverted into a too flushed sheen. Tongue gliding across my upper lip collecting salty drops only dries out the dessert that is my mouth. I did not think roots could grow without water, but one has managed to burst through.*

*“Herpes simplex virus 2,” I choke. I gaze only at the corner, begging my rooted heart to release its vicelike grip. Praying that I can be saved by the medicalese. The*

*jumbling of unknown wording too much for a quick understanding. A lack of interest, a barrier to further investigation. Do other herpes infected individuals use medical terms as a security blanket? Attempting to hide in plain sight, a partial disclosure, a way to make the disclosed to other shoulder the work. Do they feel like me? Scared to give the colloquial name in fear of transforming the boogiemana into flesh. Removing the invisibility cloak from a diseased infected monster for all the world to gawk at.*

*“Oh, right. Right,” she seemingly remembers as I am jolted back to the reality of the room. The gleam I see in her eyes creates a stampede barreling through my body. Friction from the many hooves cauterizing the tears they inflict, their heat radiating through my pores. I ride the storm of their indignation. She knew! Do they know now? Have they figured out the puzzle? Understand that I am writing an personal vignettes about having genital herpes. That I am carrying around so much septic flesh.*

*Do they even care? A splitting sky of freezing rain drowns the stampede. Left cold, teeth aching as if they have done nothing but chatter for the past seven months. Do they see the whites of my eyes flashing before them? The person I was sinking below the depths leaving behind only the memory of*

*Katrina, the girl with herpes.*

*Katrina, the girl that studies herpes.*

*Katrina, wow so brave for putting herself out there but I could never be with someone who has...herpes.*

*Not that Katrina, herpes Katrina.*

*Never just Katrina, only an incurable disease.*

*Writing about disclosure was meant to lift the weight, not become my anchor.*

\*\*\*

The impetus for this thesis was to develop a better understanding of the disclosure patterns of individuals with genital herpes. After current research studies were investigated, two research questions were used to guide the process for this thesis: 1) How do those with genital herpes come to the decision to reveal or conceal their status?, and 2) What does disclosing their status mean to people with genital herpes?

The first chapter was an introduction to the current conditions of genital herpes and its associated research. The second chapter discussed the literature surrounding STI and genital herpes disclosure patterns. Additionally, the second chapter focused on current communication theories surrounding disclosure. Within the third chapter I described the methodology that was used to direct this research project. In chapter four I provided the major three major themes that emerged from participant interviews: influencers on disclosure, barriers to disclosure, and genital herpes contradictions. This final chapter discusses answers to the established research questions and their associated implications, the limitations of the study, and how future studies could be directed. The chapter will close with a personal reflection about the experience of the conducted research.

### **Research Question 1**

The first question that this thesis was meant to answer was the ways in which those with genital herpes come to the decision to reveal or conceal their status. When it

comes to the patterns of disclosure for those with genital herpes it is not surprising that many of their patterns echo certain findings from previous studies or are demonstrative of Petronio's (2002) CPM and Greene's (2009) DD-MM theories. However, the findings from my research indicate that those with genital herpes engage these theories in unique ways that separates it from previous research conducted. The patterns of revealing and concealing a genital herpes status emerged through this research in a few significant ways that help to address this research question.

This research indicates that those with genital herpes choose to reveal their status based on certain criteria. By making the decision to disclose their status, those with genital herpes are attempting to protect themselves including their own time and effort as well as a particular closely held self-image. Disclosing as a way to protect the self differs from the Bickford et al. (2007) that indicates that restricting disclosure is done as self-protection. These participants also disclosed their status in order to protect their potential partner from transmission, which runs counter to the findings of Green et al. (2003) where concern for the relationship outweighed concern for potential transmission.

Additionally, my participants indicated that they disclosed their status in order to obtain emotional support after experiencing the traumatic event of a herpes diagnosis, which aligns with the Petronio (2002) understanding that this type of event can impact disclosure rules, however, the specific need to obtain emotional support as an impetus for disclosure is specific to these genital herpes participants. At other times, my participants felt that they almost did not have a choice but to disclose their status due to the fact that significant others were already aware that something was wrong. We can understand this theme through the CPM notion that occasionally boundary linkages are outside of our

immediate control. Finally, those with genital herpes disclose their status when they view the disclosure as necessary to maintaining a certain relationship.

This thesis data closely aligns with current research when it comes to the concealment of a genital herpes status. When my participants indicated that they refrained from disclosure it was predominately associated with a fear of potential stigmatization due to the sexual nature of the virus. The desire to abstain from being thought of as a whore or slut left most participants wary of revealing their status. Through the lens of DD-MM (2009) we can understand how this anticipated response is likely to continue to impact the rates of disclosure of those with genital herpes, where one that is negative will prevent those with the virus from disclosing a positive status. Finally, these participants made the decision to conceal their status as a means to control their information. This control is demonstrated by restricting certain topics with significant others and by being cognizant of the potential of their information to go beyond their intended recipients. Whether due to fear of stigmatization or a desire to control their private information in both instances those with genital herpes are making the choice to conceal their status.

## **Research Question 2**

It would be simple to state that when those with genital herpes disclose their status it means that they are upholding the themes identified for disclosure. That it means that they are attempting to protect themselves and potential partners. It could also mean that they are reaching out for necessary emotional support during a life-changing situation. Finally, we could even interpret the meaning of a genital herpes disclosure as an attempt to maintain certain expectations and ideals of a given relationship. However,

while all of these statements are valid they miss other important aspects of the meaning of a genital herpes disclosure.

When a person discloses a genital herpes status to another it means that they are willingly stepping into a moment of great risk and vulnerability. They have decided that they are willing to lay, at least a part of, their sexual history bare even in the face of potential stigma, but have decided the benefits of disclosure far outweigh the associated risks. The meaning of a genital herpes disclosure is the embrace of vulnerability despite the fear of not only other's potential negative perception, but their own negative sexual self-perception. With each disclosure, especially when paired with a positive response, those with genital herpes are able to reestablish a positive sexual self-image, which was distorted through their diagnosis.

Finally, for those with genital herpes disclosing means that they are put into a position where they have to negotiate contradictory ideas about their own perspectives and expectations. My research demonstrated three major tensions that occur for those with genital herpes, including the perceived seriousness of the virus, the level of partner acceptance, and their own lack of reciprocity acceptance. It is through the act of disclosing that these tensions are realized and expressed. By disclosing it means that those with genital herpes are verbalizing this contradictory ideas that are not always, if ever, resolved, but rather must be dealt with each time they are encountered.

### **Limitations**

This study has helped to fill a gap in the research surrounding the disclosure patterns of those with genital herpes. However, there were some limitations about the study that should be discussed. First, all participants in this study identified as female.



While this still has benefits as the infection rate and frequency of genital herpes is higher for females, it does not take into account the experiences of males. There is the chance that males will have different experiences and motivations surrounding the disclosure of their genital herpes status. Additionally, only one participant identified as being homosexual. Expanding the study to include more sexualities would not only bolster research about those marginalized communities, but may provide evidence of difference and similarities between styles of disclosure for the various sexualities. Finally, with the exclusion of one participant, all other participants identified racially as white. The exception being one who identified as African-American. Even though interesting content about the influence of race on genital herpes was elicited, unfortunately, there was not enough diversity to compare the information.

Another limitation to the study is that all participants had contracted genital herpes without knowledge of the potential risk. Meaning that none of the participants had the opportunity to be aware of a previous partner's condition and make the conscious decision about accepting the risk of contraction. Unfortunately, only one participant spoke directly about how the situation of contraction influences their disclosure and, as such, no explicit comparisons can be made. However, it is likely that circumstances around the initial experiences of contraction impact disclosure decisions. Therefore, those that choose to accept the risk with a partner who then learn about a positive diagnosis may have different disclosure patterns when it comes to their genital herpes status.

## **Future Studies**

Considering the results and limitations for this study there are multiple aspects that future studies could investigate. First, this study should be expanded to include a more diverse representation of those with genital herpes. This would include ensuring more representation from diverse sexualities and racial identities. Additionally, future replications of the study should include the perspective of males to reflect potential sex differences in disclosure patterns. Finally, similar future studies should also include questions that take into consideration the circumstances of contraction along with their potential to impact disclosure-decision making.

Second, this study focused on participant interviews to uncover the patterns of those with genital herpes. Due to the stigmatizing nature of herpes participation in such interviews is likely to be limited. Future studies could focus on more digital artifacts to discover similarities or differences in disclosure patterns. Digital artifacts could include online support groups, chatrooms, phone apps, or blogs that target those with genital herpes. Easier accessibility and greater repository of information in the form of digital artifacts could broaden the understanding of the how those with genital herpes disclose their status to others.

Third, almost all participants indicated that when they were diagnosed they began looking for additional information about the virus. Only one participant indicated that they did not have access to additional information, and was also the only one who had not disclosed their status to anyone outside of myself. Future studies could focus on not only information gathering of those with genital herpes, but also how the ability to obtain information impacts the decisions around disclosure. Also, with the dissatisfaction that

participants held about their disclosing practitioner, future studies may want to focus on how practitioners relay a positive status and what information they provide.

Finally, future studies could focus on obtaining more knowledge about the double-binds that those with genital herpes experience. Whether it is about the seriousness of the virus, the level of partner acceptability, or acceptance reciprocity further investigation is warranted to understand how they are expressed by others with genital herpes. Furthermore, it would be beneficial to see if there are other double-binds that are experienced. Additionally, these double-binds could be investigated for occurrence with other STDs such as, HPV or HIV/AIDs.

### **Reflection**

The entire impetus for this project was nestled into my own search for understanding the new reality of living with genital herpes. I wanted to study how others disclosed because I was desperately trying to figure it out myself. I hoped that through this process I would be better able to handle my own diagnosis. Reading the, though limited, research, interviewing others, and writing through my vignettes has allowed me to find moments of catharsis and support that otherwise may have been difficult to obtain. However, it has also forced my disclosure in some ways requiring me to create collective boundaries where I might have rather held a private one.

When there is such a high level of personal connection to a project, it can make the work extremely difficult, even if it may also be beneficial. When Heather expressed that when she disclosed her status she was forced to face the reality of her diagnosis each time, I understood completely because it is the same when you must write about it. Each time that I had to work on this study I had to face the reality that my sexual health was

compromised. That I would never get away from having to make the decisions about whether to disclose, and the repercussions of those choices. Every hour spent working with the material a reminder that my sex life was going to be forever changed, and certain relationships forever closed. It's not easy or pleasant to constantly reflect on these moments, which is why the study has, at times, been extremely strenuous.

It would be amazing to be able to state that after the completion of this project I have disclosure down to a science and can do it with ease, but I can't and I don't think I ever will. For me, it will never be easy to step into that moment of vulnerability and risk when it comes to disclosing my genital herpes. Even though I know that the stigma and judgment is only socially constructed, it ricochets in the back of my head every time I approach the situation.

Additionally, I am half black and half white, but have grown up with white parents in a predominantly white neighborhood where I went to predominantly white schools. I go to a predominantly white college where I hang out with predominantly white students and have been taught by predominantly white teachers. There have been times where I have legitimately forgotten that I am not like them, until I am faced with a moment of racism and suddenly remember. When I found out that black women experience higher rates of genital herpes I was confronted with my blackness. It happened again when I had to listen to a white participant complain about how she would not feel comfortable attending a black genital herpes support group and complained about how it was unfair that it was targeted for them. Then again when I listened to my one black participant echo my own fears that when standing next to our white sisters with genital herpes, it is us who will be viewed of as dirty. In every moment, I am forcibly

reminded that no matter how comfortable I may feel, how woke the group is, or that I am also half white, I will always be a black woman constantly othered.

Although not my intention, this research still perpetuates the standard of expressing white women stories over those of women of color. My research, like so much research before me, has placed white stories at the center while leaving those from people of color on the periphery. Yes, considering my available population it is understandable that the majority of my participants are white. I also never brought up race explicitly with my white participants as I didn't want to alienate the women who were already feeling vulnerable. However, it is still necessary then for those in academia and beyond to push for the stories of marginalized communities, especially women of color, to no longer be considered secondary or supplemental.

## Appendix A

### Consent to Participate in Research

#### Identification of Investigators & Purpose of Study

You are being asked to participate in a research study conducted by Katrina Miles from James Madison University. The purpose of this study is to understand the disclosure patterns and processes of individuals with HSV-2, genital herpes. This study will contribute to the researcher's completion of her master's thesis.

Should you decide to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of an interview that will be administered to individual participants in the participants preferred location. You will be asked to provide answers to a series of questions related to your experiences with disclosing or not disclosing your genital herpes status to others. These interviews will be audio-taped with participant consent. Should individuals not want to be audio-taped extensive field notes will be collected by the researcher.

#### Time Required

Participation in this study will require approximately 45 minutes of your time.

#### Risks

*There is a possibility through participation in this research an individual may experience significant emotional or mental health issues due to recounting of sensitive moments. In order to protect participants local and online resources will be provided to help process any feelings associated with participation. The online resource provided will be through the site Dating With Herpes, <http://datingwithherpes.org/>, this site provides additional information and social/support groups for those with herpes. Local resources will be determined based upon participation location; all efforts will be made to find an appropriate local source for assistance. The participant may at any time select to take a break from the interview process. At that time the interviewer, Katrina Miles, will determine whether the participant would like to continue the process. Should the participant choose to discontinue the process all obtained data from the interview will be immediately deleted and the session will be considered over. All efforts will be made to protect the identity and health status of participant (see below security procedures).*

#### Benefits

Potential benefits from participation in this study include your ability to share your disclosure experiences. There are potential benefits for communication scholars and

health practitioners to develop a better understanding of genital herpes disclosing patterns.

### **Confidentiality**

The results of this research will be presented at a thesis defense and presentation, at academic conferences, and published in academic journals. The results of this project will be coded in such a way that the respondent's identity will not be attached to the final form of this study. The researcher retains the right to use and publish non-identifiable data. While individual responses are confidential, aggregate data will be presented representing averages or generalizations about the responses as a whole. All data will be stored in a secure location accessible only to the researcher. Upon completion of the study, all information that matches up individual respondents with their answers, including audio files, will be destroyed.

### **Participation & Withdrawal**

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

### **Questions about the Study**

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

Katrina Miles

Heather Carmack

School of Communication Studies

School of Communication Studies

James Madison University

James Madison University

mileskc@jmu.edu

carmachj@jmu.edu

### **Questions about Your Rights as a Research Subject**

Dr. David Cockley

Chair, Institutional Review Board

James Madison University

(540) 568-2834

[cocklede@jmu.edu](mailto:cocklede@jmu.edu)

### **Giving of Consent**

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory

answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

☐ I give consent to be audio-taped during my interview. \_\_\_\_\_ (initials)

\_\_\_\_\_  
Name of Participant (Printed)

\_\_\_\_\_  
Name of Participant (Signed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Researcher (Signed)

\_\_\_\_\_  
Date

Sample consent forms and cover letter:

<http://www.jmu.edu/researchintegrity/irb/forms/index.shtml>



## Consent Guide for Telephone/Skype Interviews

### VERBAL CONSENT DOCUMENTATION FOR PARTICIPATION.

SUBJECT: “So, I have Herpes”: A Qualitative Investigation of the Disclosure Patterns of HSV2 Individuals

Oral consent serves as an assurance that the required elements of informed consent have been presented orally to the participant or the participant’s legally authorized representative.

Verbal consent to participate in this telephone/Skype interview has been obtained by the participant’s willingness to continue with the telephone/Skype interview by providing answers to a series of questions related to the participant’s experiences with HSV-2, genital herpes, disclosure.

\* Phone/Skype Script: See Consent form as that will be read verbatim to the phone/Skype participants

I attest that the aforementioned written consent has been orally presented to the human subject and the human subject provided me with an oral assurance of their willingness to participate in the research.

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Surveyor’s Name (Printed)

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Surveyor

## Appendix B

### Participants Needed!

My name is Katrina Miles and I'm a graduate student in the School of Communication Studies. I am conducting research about how individuals with genital herpes make the decision to disclose their status.

I am looking for participants who would be interested in being interviewed as a part of this study. Participants must be at least 18 years old and have been diagnosed with HSV-2, also known as genital herpes. If you are interested, we can schedule a time to conduct the interview. Interviews may be done face-to-face, over the phone, or via Skype. These interviews are expected to last about 45 minutes.

Participation is voluntary and your identity will remain confidential.

If you are interested, please contact me at [mileskc@dukes.jmu.edu](mailto:mileskc@dukes.jmu.edu).

## Appendix C

### Interview Research Protocol

- How do you make the decision to disclose your genital herpes status?
  - If you have told family members about your diagnosis, what brought you to that decision to disclose? How has that conversation gone? If you haven't, what has prevented this disclosure?
  - Have you told any friends? If yes, how did you make that decision? How did you bring up that conversation? If you haven't, why not?
  - When did you decide to disclose to your current or past partners? What brought about those instances of disclosure? How did you bring up the topic?
    - Before you disclosed to your partner, did you (always) practice safe sex? Did you continue to practice safe sex after disclosure? Did any of your sexual practices change after your disclosure to your partner?
  - What type of reactions have you had when you disclose? How did they feel?
- How did you react when you were first diagnosed?
- What type of interaction did you have with your disclosing practitioner?
- Were you given any methods or advice on how to disclose to partners?
  - If yes, what were they and have you found them helpful?
  - If not, what do you wish you were told?

- Has your diagnosis changed any of your sexual practices? How so? What about safe sex practices?
- In what instances do you make the choice to not disclose? Why? Do you practice safe sex during those times of non-disclosure? Why?
- What does it mean to disclose your status?

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